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SUBJECTIVE
EXPERIENCES OF
DIGNITY WITHIN
MENTAL HEALTH
CARE

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1 ABSTRACT

Background: The importance of respecting people's inherent dignity was put on the agenda during the last century with the United Nations Universal Declaration of Human Rights. From a caring science perspective, the importance of meeting people with respect and taking care of their absolute dignity is also emphasized. Despite all this, patients at psychiatric hospitals still experience suffering and reduced dignity.

Aim: The overall aim for this research was to explore patients', relatives' and staff members' views concerning patient dignity at mental health hospitals. In paper I, the aim was to gain a deeper understanding of how the staff in a psychiatric hospital perceive dignity in their encounters with patients and their understanding of what influences a patient's experience of dignity. In paper II, the aim was to gain a deeper understanding of the subjective experiences of patients in a psychiatric hospital with respect to dignity. The purpose in paper III was to reveal relatives' opinions regarding what is important for ensuring the preservation of a patient's dignity when they are admitted to a psychiatric hospital. In paper IV, the focus is on common experiences of patients and relatives in terms of how the dignity of the patient was taken care of when they were admitted to psychiatric hospitals.

Method: Two different methodological approaches have been applied. In studies 1, 2 and 3, a Q methodological approach was applied. Based on a Q sort (a collection of statements) developed from qualitative interviews, staff members, patients and relatives were instructed in sorting 51 statements. Patients were asked to order the statements in a grid from those they most agreed with to those they most disagreed with. Relatives and staff were asked to rank the statements based on what they felt was relevant for the patients' experience of dignity. Post-interviews were performed, with all the participants immediately after they had sorted the statements. The analysis of data was done by performing by person factor analysis for all the patient-, relatives- and staff studies (papers I- III). In study 4, a Phenomenological hermeneutics method for researching lived experience guided the analysis of qualitative interviews conducted with patients and relatives.

Results: In *study 1* (paper I), 25 staff members participated and two different viewpoints emerged. Viewpoint 1 was given the name: 'Patient Focused Staff', while viewpoint 2 was called, 'Challenges for Staff'. In *study 2* (paper II), 15 patients participated, and four different viewpoints emerged. Viewpoint 1 was described as, 'Being met as equal human beings'. Viewpoint 2 was named, 'Experience of dignity despite suffering'. Viewpoint 3 was interpreted as, 'Suffering due to feeling inferior'. Viewpoint 4 was described as, 'Suffering and fighting for one's own dignity'. *Study 3* (paper III), was about relatives' viewpoints. Thirteen relatives participated and four different viewpoints were identified. Viewpoint 1 was named 'Value based', viewpoint 2 was about 'Expectations', viewpoint 3 was given the name 'Asymmetric', while viewpoint 4 was described as 'Nuanced'. In *Study 4* (paper IV), one main theme and four sub-themes were revealed. The main theme was described as, 'The significance of small things for the experience of dignity', while the sub-themes were described as, 'To

be conscious of small things', 'Being conscious of what one says', 'Being met' and 'To be aware of personal chemistry'.

Conclusion: Within each group of patients, relatives and caregivers, differences but also consensus were found. Also similarities across the studies were found. The staff's way of meeting patients and relatives has a direct influence on the patient's experience of dignity. In encounters where the patient's- and relatives' experience of being met by staff represents values such as equality and respect for humans' uniqueness, they experience that the patient's dignity was being taken care of. All staff members also emphasize this, with some staff also focusing on challenges related to this. Some patients and relatives communicate that there still is an imbalance in their relationship with carers, which is something that increases a patient's suffering. Other patients and relatives sometimes found it necessary for the staff to take control over the patient's situation. For caregivers, being aware of their responsibility towards a patient's suffering opens up an opportunity for a compassionate self in an authentic encounter with patients. As discussed in paper IV, how staff members behave, in addition to putting a focus on small things in each unique encounter with patients in a dignity promoting- or dignity inhibitory way, reveals to what degree the staff are aware of their ethos, as well as to what degree both the individual staff members and the caring culture can be experienced as being ethical or not ethical.

Key words: dignity, suffering, psychiatric hospital, patient, relatives, staff members

LIST OF PUBLICATIONS

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- II. Skorpen, F., Thorsen, A., A., Forsberg, C., & Rehnsfeldt, A., W. (2014). Suffering related to dignity among patients at a psychiatric hospital. *Nursing Ethics*, 21(2), 148-162
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1 INTRODUCTION

From a historical perspective, is it possible to learn that how society views mental suffering is not only a question about suffering in and of itself, but just as much a question as to what way of understanding the suffering benefits society (Foucault, 1973). In around 1820 –30 in both Europe and the US, treatments based on “moral treatment” and principles such as respect, kindness and dignity, but also use of force and control, was applied when necessary (Høyersten, 2009), and these principles are much the same today as they were 200 years ago. Over the past 30 years, mental health services in Norway have undergone a major change. The number of beds at psychiatric hospitals have been reduced from approximately 12,600 in 1980 (Weekly Statistics, 1996) to around 4,500 in 2011 (Statistical yearbook of Norway 2013). Nevertheless, there are still approximately 1,350,000 bed – days at psychiatric hospitals in Norway every year (Statistical yearbook of Norway 2013). In a report from Western Norway, they reported that 20% of all patients admitted to wards at psychiatric hospitals in that area experienced psychosis. It was also reported that 80% of economic recourses at those wards were used for taking care of this group of patients (Gjævar Syrstad, 2012). Being met by professional caregivers in a way that takes care of them as well as possible is important, not only for the patients themselves, but also for their families.

There has also been a change in the way in which the experiences of those who are being patients are seen as equivalent knowledge compared to a more traditional view of knowledge based on professionals’ views (Ekeland, 2011). A report from the Social and Health Services in Norway (2006) says that user participation has an obvious value in that people seeking help, in line with others, would like to have control over important parts of their lives, receive assistance on their own terms and be seen and respected in the power of their basic dignity. There has also been a major change insofar as that while relatives were previously seen as part of the cause of the patient's illness, they are now being seen as important for patient alleviation (McFarlane, Dixon, Lukens & Lucksted 2003). But despite the fact that dignity as a concept has been highlighted in both the United Nations Universal Declaration of Human Rights (United Nations, 1948) and professional ethical guidelines, such as the Code of Ethics for Nurses (ICN 2012), research over the last few decades has shown that being a patient with a mental illness is related to stigma, shame and reduced dignity (Hagen & Nixon, 2011), and that the relatives of these patients have to live with sorrow, anguish and constant worry (Pejlert, 2001).

The context of this study is patients, being admitted to a psychiatric hospital which one or more times have experienced being psychotic. Also relatives to patients experienced being psychotic one or more times and staff members worked on units caring for patients with a history of psychotic episodes participated in this study. More knowledge about patients’, relatives’ and staff members’ experiences regarding taking care of the patient would benefit the individual patient, their family, the professional health-care system and society as a whole. Based on an epistemological view that acknowledges patients’, relatives’ and staff members’ knowledge as equivalent knowledge, as a

starting point we want to ask patients, relatives and staff members about their subjective experiences with regard to take care of patients dignity.

Theoretical foundation for understanding the findings are built on a caring science perspective about human beings interdependence, inherent dignity and ability for suffering (Lindström, Lindholm & Zetterlund, 2010). Methodological approaches, Q methodology and Phenomenological hermeneutical method for researching lived experience are chosen for the purpose of exploring these participants' experiences. Thus, new knowledge and a deeper understanding based on their experiences can then arise.

2 BACKGROUND

Throughout history, dignity has been described in several ways, and relevant sources for this thesis can now be described. Dignity can be seen as both something inherent, belonging to all human beings, and as something relative and changeable. Dignity is also described as a major concept within the Theory of Caritative Caring, and within this theory the relationship between dignity and suffering is also described.

Mann (1998) says that people use quite a bit of energy in their daily lives to preserve their dignity, as small things, symbols, actions, etc. can escalate to become very significant for them. To not lose one's face is a good illustration of this. Mann also says that naming a phenomenon, such as dignity and a violation of dignity is of importance. Once one has set a name to, or described a phenomenon, it seems as though it is much more extensive than first thought. To put a name on it, and describe and classify it, is a necessary step towards an informed awareness (Mann, 1998).

The concept of dignity has also been criticized for being vague and unclear, even if from a human rights perspective it was used to make a point about the concept in general, and not tied to any specific culture, religion or political opinion (Lindholm, 2009). But one consequence of this general description of dignity is that its vagueness and lack of clarity can lead to arguments that represent the opposite (Caulfield & Brownsword, 2006). Additionally, if one is looking at dignity from a Christian religious perspective, one is excluding other spiritual and religious perspectives (Lindholm, 2009). Professor of medical ethics Maclin (2003) asserts that because of its vagueness dignity is a useless concept to attempt to study. Jacobson (2007) Nordenfelt (2004), Eriksson (2006), Edlund (2002) and (Edlund, Lindwall, Post, & Lindström, 2013), they all make a distinction between dignity as something absolute and something relative.

2.1 DIGNITY FROM VARIOUS PERSPECTIVES

Historically, in ancient Greece and Rome dignity was tied up to a person's position in society (Barbosa da Silva, 2009). The renaissance humanist Pico della Mirandola (2013) described human dignity as a result of God giving humans the ability to create their own future, their moral superiority and a responsibility in relation to both other living beings and all other things in the universe (Pico della Mirandola & Frost, 2013). According to Immanuel Kant, human beings' dignity is in their rationality and their capacity to make moral decisions based on principles and not instincts. Kant also meant that human beings should be seen not as just a means for archiving something, but as an end in itself (Rachels & Rachels, 2012). According to Barbosa Da Silva (2009), this secular way of understanding dignity can be found in the Universal Declaration of Human Rights' first article, which says that, "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood" (United Nations, 1948). According to Nordenfelt (2004) the ideal of equal human value is commonly accepted and found in

religions, as well as in Western secular ideology. In a Norwegian dictionary dignity synonyms translated to English as worthy (verdig), seriously (alvor), compulsion (fatning), highness (høyhet), pondus (pondus), position (posisjon), rank (rang) status (status), honour (ære) and merit (fortjeneste) (Berulfsen & Gundersen, 2012) Synonyms for worthy (verdig) are deserved (fortjent), qualified (kvalifisert), serious (alvorlig), restrained (behersket), significant (betydningsfull) distinguished (fornem), proud (stolt), dignified (ærverdig). English synonyms for dignity are exaltation, face, grandeur, honor, importance, majesty, nobility, rank and status (English Synonym Dictionary, 2014)

2.1.1 Dignity as something relative and changeable

As described, dignity can be seen as something inherent that belongs to all human beings, but dignity is also described as something relative and changeable. Mann (1998) says that dignity seems to come from two perspectives: how I see myself (inner dignity) and how others see me (outer dignity). The experience of personal dignity involves a process that includes both internal and external components. One can find extreme variations of dignity in which dignity can be experienced despite very adverse conditions, while by contrast unworthiness can be experienced despite a very positive environment. For most of us, it seems as though the interplay between internal and external factors seem to be constant, variable and changing (Mann, 1998).

2.2 A CARING SCIENCE PERSPECTIVE ON DIGNITY

From a caring science perspective, “Human dignity is partly absolute dignity and partly relative dignity” (Lindström et al., 2010 p. 196). Absolute dignity is a position which is given to human beings through creation, and is a unique position among created beings (Edlund et al., 2013). One of the caring science’s basic assumptions says that, “The human beings are fundamentally holy. Human dignity means accepting the obligation of serving with love for the sake of others” (Lindström et al., 2010 p. 198). Dignity is based on a source of values that are “holiness, human worth, freedom responsibility, duty, and serving one’s fellow-men” (Edlund et al., 2013 p. 858), and these values are absolute and impossible to renounce. Dignity cannot exist without the element of absolute dignity.

From a caring science perspective, dignity is also described as something relative and changeable, which is influenced by one’s experience, situation and culture (Edlund et al., 2013). A person’s relative dignity can be both destroyed and re-established. Relative dignity can be seen as an inner ethical, psychical dimension that confers an awareness of one’s own- and other’s dignity. One’s spiritual dimension of human entity is to be found here, while honesty, justice, independence, communion, credibility and esteem are also empirical values that belong here. This type of dignity highlights the importance of behaving in accordance with values formed by the society one is living in. Relative dignity also includes an external aesthetic dimension that belongs in the bodily dimension of the human entity. Empirical values found that belong here are

properness, suitability, self-command, composure and orderliness. The significance of experience formed by characteristics, events and actions varies from being of great importance for each human being to being of no importance (Edlund et al., 2013).

2.3 SUFFERING AS A RESULT OF VIOLATED DIGNITY

The consequences of not being taken care of with dignity can result in increased suffering. About suffering and dignity, Mann (1997) says that:

An exploration of the meanings of dignity and the forms of its violation - and the impact on physical, mental, and social well-being may help uncover a new universe of human suffering, for which the biomedical language may be inapt and even inept (Mann 1997 p. 10).

In accordance to Eriksson (2006), to experience suffering is an inseparable part of human being, and suffering and health are each other's prerequisites. There is a variety of forms of suffering and reasons why people suffer. From a caring science perspective, one is talking about the suffering of life, the suffering of illness and the suffering of care. These different kinds of suffering are intertwined with each other. Eriksson (2006 p.79) refer to Florence Nightingale, who says that "How little the real suffering of illness are known or understood. How little does any one in good health fancy him or even herself into the life of a sick person" (Nightingale, 1969 p. 101). The suffering of care takes place in situations of care, with violating the patient's dignity being the most common form of suffering (Eriksson, 2006). Violating the patient's dignity can occur in different ways such as through direct and concrete actions from the carer, but also through neglect, that the carer does not see the person or through deficient ethical conduct. The consequences of insufficient care can be that it takes away a person's opportunity to be a whole and integrated person. By violating the patient's dignity, they also reduce the patient's possibility to use their innermost health resources (Eriksson, 2006).

Eriksson, (2006) also describes other types of suffering related to care: *a) Condemnation and punishment* can occur if the patients do not behave in a way that the caregiver feels is best for them, *b) Assertion of power* can happen directly or indirectly, such as not taking the patient seriously or forcing the patient to do things he or she is not able to do, and *c) Omitted care or non-care* can be anything from minor events and carelessness to total neglect from carers. Not to give the patients the care he or she needs is a way of violating human dignity and exercising power on a human being in a situation of dependence (Eriksson, 2006).

The *suffering of illness* can be a result of the illness and/or treatment related to the illness. Another type of suffering is mental and spiritual suffering. Humiliation, guilt and/or shame related to one's illness and/or treatment are also forms of suffering that can come from a feeling of not living up to expected standards for the self and /or others. The *suffering of life* is another kind of suffering. The suffering of life is related

to what it means to be human and to be in relationships with other human beings (Eriksson, 2006).

Jacobson (2012) talks about “Dignity Violations, A Universe of Suffering” (Jacobson (2012 p. 21). These forms of interactions and actions are the social process of dignity violation in health care which happens as a result of rudeness, indifference, condescending disregard, dependence, objectification, labelling, discrimination, revulsion, deprivation, assault and abjection. Some of these experiences are experienced often, whereas some are more seldom experienced. Dignity violations occur more often when there is some type of imbalance in the relationship between the parts (Jacobson 2009, 2012).

In accordance to Eriksson (1992), some kinds of suffering are unbearable. These kinds of suffering prevent people from growing. But suffering can also be seen as a process from unbearable to bearable suffering. Rehnfeldt and Eriksson (2004) call it a progression of suffering, describing it as: a) unbearable suffering, described as a darkness in life that requires an encounter involving attentive care and confrontation, b) a turning point in which the struggle for suffering begins, c) a struggle of suffering between paradoxes such as hope, hopelessness, as well as an opportunity to discover or create meaning through an existential caring encounter between patient and carers.

As this literature review shows, there is a connection between suffering and dignity. To live implies, among other things, to suffer, and suffering is a part of all humans life (Eriksson, 2006) but suffering also arises as a consequence of how one is taken care of by other people, something which can result in reduced dignity.

2.4 TO CARE FOR THE PATIENT’S DIGNITY – AN ETHICAL DEMAND

According to Eriksson (2003), ethical caring became visible through how carers do things and what they do vis-à-vis their patients. This ethical caring has its roots in some basic values or ethos. This ethos reflects the prevailing way of ranking values; it is a kind of tonal bottom that opens up for what is eternal and sacred. Ethos and ethics belong together, but an ethics developed without any ethos appears as a kind of formal ethics without any deeper basic values (Eriksson, 2003).

Karterud (2006) says that Løgstrup’s description of the ethical demand is a way to form a connection between the substance of caritative ethics and the use of it in a concrete reality. The basis for ethics is that we as human beings are ontologically interdependent on each other and that human beings are always present in situations, which is why ethical situations arise. According to Løgstrup (1997), trust, openness of speech and mercy are sovereign expressions of life. These phenomena present themselves as each one of us being intrinsically good. Trust is about taking responsibility for the other person. To hold another person’s life in one’s hand can be seen as a metaphor for this responsibility (Løgstrup, 1997).

Løgstrup also discusses how people make ethical decisions. In critical situations such as war, human beings have no choice. They must do what they have to do, without thinking of the consequences, even though it may cost them their lives. It is in these types of situations that the silent ethical demand is totally incorporated into what is being done. In normal, ordinary situations, man can either follow the ethical demand or they may refuse to do so. In normal situations, people often do not do so since they do not want to be disturbed in their convenience (Løgstrup, 1997).

2.5 EARLIER RESEARCH

Earlier research among a patient's relatives and staff members has shown various experiences with regard to taking care of the patient's dignity. In this overview of research done among all the groups of patients, relatives and staff, both dignity promoting- and dignity reducing experiences are presented in the following text. First, some relevant studies among patients would be presented. Next, some studies among relatives, then some studies among staff would be presented, and lastly some other relevant studies would be presented.

2.5.1 Earlier research among patients

According to Bramesfeld, Klippel, Seidel, Schwartz, & Dierks (2007) Staff members should not only focus on service users' mental illnesses, but also respect them as equal human beings, treat them individually, protect their integrity and help them in achieving independence. Some experienced being threatened worse because of their mental illness, thus a resistance against caregivers could be a way for patients struggle for maintaining dignity. To be treated with dignity is to be respected and treated in accordance with ordinary societal norms – something as simple as being met in the reception area at a hospital.

Patients in a psychiatric setting experience a sense of dignity when they encounter competent and committed staff members who possess self-knowledge, treat them as equal individuals, attempt to understand them and confirm them, e.g. being heard, being seen as a unique person, being taken seriously and helping them to reduce their shame. A hug or a pat on the shoulder could also be experienced as a confirmation (Schröder, Ahlström, & Larsson, 2006).

The users of mental health-care services found it to be important to be recognized as human beings, and that staff members sometimes show and share with them something of themselves. Unfortunately, participants do not experience being recognized on their own terms, even if professionals do their best (Eriksen, Sundfør, Karlsson, Råholm, & Arman, 2012).

Among patients with a vast experience with drug addiction, a restored dignity, such as being cared for with love and being heard, was essential for them to be able to create new meaning in their lives. Such care fosters a sense of dignity that grows out of a

caring and confirming relationship, allowing them to be able to view themselves from a new perspective (Wiklund, 2008).

Time on the ward was described as being kept in storage, isolated from society, left alone with a mixed group of fellow patients, as well as meeting an omniscient master who did not listen to what the patient told them. Being together with staff could also be described as a light in the darkness, in which patients felt safe and were able to relax. It was a kind of mutuality, and nursing staff treated patients as “normal human beings”. Coping strategies, adaption and solidarity were ways that patients struggled for control in the situation (Lilja & Hellzen, 2008).

The one-to-one relationship between patients and staff, including that informal conversations among them were important to patients, which is something that has to be recognized by the professional health-care services. All in all, the relationship between the patient and the staff is important for the patient’s experience of dignity (Hopkins, Loeb, & Fick, 2009)

Communication is important. A staff’s ability and willingness as humans to listen has resulted in service users feeling respected, reporting a negative experience if the staff stayed away and did not listen, while the use of coercion was experienced negatively (Gilburt, Rose, & Slade, 2008).

According to Svedberg, Jormfeldt and Arvidsson (2003), the experience of dignity is influenced by how the patients felt respected when they were listened to, that their feelings were taken seriously and not violated, and that their self-determination was respected by the nurses. To trust the patients’ capacity to make their own decisions is crucial for their motivation and development, as the nurse must take the patient seriously. If the nurse considers him/herself as the one who knows everything best, then the patients do not feel respected. Consequently, the patients who experience the health problems should define what the problem is.

Living with major depression in family life can be described as a battle between dignity and suffering, and dignity has to be constantly restored for both oneself and one’s family before being able to have a focus outside the family (Ahlström, Skärsäter, & Danielson, 2010).

In a study that asked service users how mental health nursing can improve in an inpatient setting, service users responded by saying they wanted more influence on their own situation, and more time together with an experienced staff, as well as how the ward was managed being of importance. Service users wanted modern matrons, with ward managers, to help secure that service users are treated with dignity and respect (Brimblecombe, Tingle, & Murrells, 2007).

Granerud and Severinsson (2003) found that people with mental health problems living in their own homes emphasized having control over one’s life as being important, including one’s life history, something which is a protection against a violation of human dignity. It was also important to be viewed like everyone else through a de-dramatization of mental illness, being confirmed as being like everyone else. Patients

sometimes experience a lack of respect and stigmatization due to having a mental illness, thereby affecting their dignity (Granerud & Severinsson, 2003).

Service users and mental health professionals describe that user participation has to be considered in relation to what is best for service users. Maintaining the dignity of service users involves a balance between allowing them to make some decisions with regard to their own situations, while simultaneously hindering them from making unhealthy decisions (Solbjør, Rise, Westerlund, & Steinsbekk, 2013).

The smoking room was a place where they maintained a certain dignity by being able to not only present themselves with an identity as a patient, but also with attempts to maintain their identity as civilians, and a kind of resistance against carers (Skorpen, Anderssen, Oeye, & Bjelland, 2008).

Patients at mental health hospitals construct a facade that keeps the suffering concealed for themselves and others, which serves as a protection against the shame of the patient attempting to maintain their own dignity (Fredriksson & Lindström, 2002).

Women being admitted to a psychiatric hospital experienced emotional violence and a loss of dignity, in addition a loss in the ability to self-determine, and a loss of dignity through being constantly supervised by others. They were critical to the labelling factor, which is about being marked as patients, even if carers saw that the patients were not listening to them. The women had to learn to play the “good patient”, which was expected by the mental health professionals, while the use of coercion was described as literally being stripped of one’s dignity (Hagen & Nixon, 2011).

Despite attempts at emphasizing the importance of protecting patients’ dignity, clients still report that their dignity is not always protected within mental health care. The system is still based on judgments from medical experts with a legitimate right to ignore their clients’ voices, and despite the evidence of a therapeutic effect, professionals can authorize and define a compulsive treatment against their client’s will (Kogstad, 2009).

Interpersonal skills, such as listening to the patient and seeing the patient, were defined as being important. Knowing and respecting the person was demonstrated by nurses showing an interest in the patient and their family. Nurses are not always respectful towards patients showing them resistance, with patients respecting those nurses who respected them (Rydon, 2005).

Mayers et al. (2010) studied the use of sedation, seclusion and restraint as methods against patients with acute psychosis in mental health institutions. Incidents of abuse, such as inadequate communication, the experiencing of distress and the violation of rights were also reported. The service users expressed that their rights had been infringed upon, and that there was also a lack of respect for their basic human dignity.

2.5.2 Earlier research among relatives

Schroder, Larsson and Ahlstrom (2007) found that dignity was one part of the next of kin's experience of the quality of care. Relatives primarily describe from their own- as well as the patients' perspectives. As with everyone else, the patients should be looked on through a de-dramatization of mental illness. A competent, well-trained staff that possesses self-knowledge, empathy, involvement and humor help both themselves and patients to reduce feelings of shame, confirming them as equal to everyone else, all which exerts an influence on their experience of dignity.

Ewertzon, Andershed, Svensson and Lütznén (2011) reported that confirmation could be understood as being approached with dignity, being recognized, valued and listened to.

Relatives reported a close intertwining between their own situation and the degree of support that they experienced their next of kin had received. They wanted to cooperate with the health-care services, but experienced being excluded. Relatives sometimes had to take responsibility for the next of kin's situation since mental health services rejected their responsibility, with some relatives experiencing support when the situation worsened (Weimand, Hedelin, Hall-Lord, & Sällström, 2011).

Relatives reported not being taken notice of, being excluded and having a feeling of powerlessness. They could have been a resource for the patients, but may not want to cooperate with staff as a consequence of how they are being dealt with. Relatives experience not being included in the treatment, and that the information they gave was not being taken seriously. They managed their situation by seeking information, participating in study circles and supporting other families in the same situation. There were also situations where they were listened to, and experienced being able to influence their own situation. They experienced guilt among family members, and that some old opinions were still persistent among caregivers (Sjoblom, Wiberg, Pejler, & Asplund, 2008).

Family members experienced a discontinuity and inconsistency in care and treatment, with only sporadic contact with their loved ones, a lack of or inexact information from caregivers, frustration, hopelessness, loneliness, and that no one took complete responsibility for their relatives. Information and an open dialogue relieved them of their burdens. Relatives also reported also good meetings, glimmers of hope and the experience of being listened to, referring to some nurses and some doctors (Wilhelmsson, 2011).

In a study by Pejler, parents described how different wards were experienced. At the hospital, they experienced living with sorrow, anguish and constant worry, guilt and shame in their meeting with the professionals. After that, the clients moved to a new place that they felt themselves and their clients preferred. But when clients moved to a community setting, everything was like before in the hospital. Staff and local authorities were the subjects in relatives' narratives (Pejler, 2001).

According to Marshall, Bell and Moules (2010), mental illness is a family experience and there exists a reciprocal influence so that mental illness often changes family life forever. In clinical practice, one can see family members suffering more than patients. This kind of suffering can be described as relational suffering, as a complex, intense human experience, reciprocally influenced in relation to significant others.

Lefley (1989) describes caring for people with long-term mental illness as a lifelong task. Relatives are there all the time, the ability to create emotional distance is small and their social life is limited. This is of concern since social support and a satisfactory social network are both important for them in managing their situation.

Previously, relatives were seen as part-, and sometimes even as a cause, of a patient's suffering. Now, relatives are seen as vital for patients' health (McFarlane et al., 2003).

Relatives of patients with severe mental illness reported poorer health than the general population in Norway. They experienced a greater burdening and a lower social health, with more women than men being single or divorced, something which can explain their reporting of a greater burden among women. Financial problems were also reported (Weimand, Hedelin, Sällström, & Hall-Lord, 2010).

Relatives experienced guilt because of not providing support for those with the illness. They felt physically exhausted and worn out as a result of the large responsibility and lacked support, all of which resulted in a feeling of being forsaken and decrepit. Some participants also reported tiredness, fatigue and a bad temper (Wilhelmsson, Graneheim, Berge, Johansson, & Åström, 2010).

Relatives experienced their life as a balancing act between different types of concerns such as talking with others about their situation, while at the same time saying too much about the patient. To what degree should one let the patient live in accordance with their own choices, or take a guard-like position over their daily life, treatment and financial support. Relatives describe warm feelings toward patients, while at the same time questioning the priorities between them and other family members. It was also a question about prioritizing between patients and their own needs. Relatives had to struggle between a wide range of feelings and a search for hope and meaning (Weimand, Hall-Lord, Sällström, & Hedelin, 2013).

Family members living with people suffering from a major depression reported not having control over their everyday life, such that the entire family became inactive. They experience uncertainty and instability, which affected their life, e.g. in relation with the limits of their financial position. They experience living on the edge of the community, with children being afraid of disturbing their parents and uncertain about their condition. In some families, the depressed family members only managed doing what was essential, while in others families they managed to do fixed routines. They also found ways out of- and to manage the situation (Ahlström, Skärsäter, & Danielson, 2009).

Relatives of patients with mental illnesses often experience an inadequate assistance from health-care professionals, experiencing a high level of burden and suffering from

stress. Family distress reflects the family's demand causing an imbalance of resources, something which affects the entire family (Saunders, 2003).

2.5.3 Earlier research among staff

Wiklund Gustin and Wagner (2013) explored clinical teaching nurses' understanding of self-compassion as a source of compassionate care. Compassion, described metaphorically as, "The butterfly effect of caring" Wiklund Gustin and Wagner (2013 p. 180), is the overall theme underlying the grasping of the meaning of compassionate care, and is about how the experience of compassion in the moment can result in and make a huge change later on. Compassionate care is about incorporating an intentional and mutual process of giving and receiving. Moreover, a compassionate self, as well as self-awareness skills would allow the caregivers to be able to meet the self and others' vulnerability and dignity in a compassionate way.

According to Hem and Heggen (2004a), compassion challenged nurses in their daily encounters with patients, and compassion needs to be more than good intentions. Staff members who communicate compassion without taking patients' signals seriously abuse their power, which is something that can result in violating a patient's dignity.

Caregivers found themselves promoting patients' dignity, thus allowing themselves to be touched by patients' stories, letting their patients share with them their worries, fear and anxiety, and sometimes being the patients' voices (Lindwall, Boussaid, Kulzer, & Wigerblad, 2012).

Fredriksson and Eriksson (2003) analysed the ethical foundation for a caring conversation. In the relationship between carers and suffering, human beings in one part of the relationship are in a position of passivity as a result of suffering; therefore, the relationship between them is asymmetric. Such a situation has the potential to be unethical if it is not balanced by reciprocity. In situations like this, the ethos of *caritas* guides carers in their encounter with human suffering (Fredriksson & Eriksson, 2003).

In accordance with Sanna and Granerud (2009), staff values such as respect, freedom and happiness are a good starting point for creating a caring relationship between patients and staff. But there were also challenges, as self-determination requires a relationship that lasts for some time. Autonomy is a human right that can be reduced, but dignity is something which no one has the right to take away from patients.

Adults with a serious mental illness should be treated with dignity and competence, and as full collaborators in service planning, delivery and evaluation. Staff should also use language and behaviour that consistently reflects and enhances the dignity of individuals with a mental illness (Coursey et al., 2000).

Dziopa and Ahern (2009) found that for creating a therapeutic relationship with patients, mental health nurses used different approaches such as equal partners, senior partners and protective partners. But in all of the various groups of staff, always being polite and treating the patient with dignity was ranked as being the most important.

A staff's education, experiences, reflection, patience and ability to communicate without provocation were all factors creating an alliance and trustful relationship towards patients (Salzmann-Krikson, Lutzen, Ivarsson, & Eriksson, 2008).

The psychotic patient with expectations of being cared for by staff could experience being rejected as a consequence of that staff meeting them not in a personal encounter, but with professional routines. Rejection for staff members can also result in developing a negative professional understanding of themselves, which is something that can also result in a reduced dignity for patients (Hem & Heggen, 2004b).

By not respecting patients' self-determination, by giving patients sedatives by force instead of talking with them and by letting them wait without explaining why, health-care staff violate patients' dignity. Patients are particularly vulnerable in situations where nurses do not respect their decisions, even if patients have the right to decide for themselves (Lindwall et al., 2012).

Staff also pointed at some challenges in the patient – staff interaction. Sanna and Granerud (2009) found that it was a balance between giving patients responsibility for their own life and taking control care of them when it was needed. Sometimes, a patient's autonomy could be reduced, even if it was a violation of human rights.

Salzmann-Krikson et al. (2008) found that taking physical control over patients involves the risk of insult. By responding to patients with dignity and sensitivity, the impact of the insult would be reduced.

Austin, Bergum and Goldberg (2003) reported that nurses in mental health care experienced moral distress and a lack of resources, which leads to dispiritedness, a lack of respect and an absence of recognition (for both patients and staff), something which diminished their ability to provide care and treat the patient with dignity. Austin referred to Florence Nightingale Nurses, describing how nurses need both flashlights and hammers, flashlights to shine a light on each patient to bear witness to their suffering and hammers to work for constructive changes.

According to Coursey et al. (2000), it was important for staff to participate in public education and advocacy by providing accurate information about persons with mental illness by identifying and challenging situations that are stigmatizing and discriminating, and by advocating for policies and procedures that respect individual rights and dignity.

Respect and humanity were key concepts to describe the therapeutic caring relationship between patients and staff. There is also a difference between having a theoretical understanding and having experience in caring for those with a mental illness. Some staff had a natural talent for relating to suffering people, while others had to work harder to achieve such skills. Discussions that involve being honest and sincere are proposed as being a precondition for creating a relationship, and sensitivity to the patient's vulnerability is also important. Hence, staff can put themselves in the patient's situation and be emotionally affected by it (Karlsson, 2007).

According to Gustafsson, Wigerblad and Lindwall (2013), nurses in forensic care expressed that the maintenance of patients' dignity is about protecting the patients' needs, as well as arousing the patients' protection resources to cover the screen and to guard against danger. It is also about teaching the patient to create respect, to teach the patients to express respect, to take the patients seriously and to show others that the patient is someone to be reckoned with. It is also about making an effort to do the little extra to show some human kindness.

2.5.4 Some other relevant studies

Relatives of elderly people in Scandinavia describe a caring culture that takes care of the patient's dignity by creating a sense of at-homeness, thereby allowing the resident to feel safe at once upon arrival at a nursing home. Dignity is also experienced when the nursing staff does the little extra- or small things, such as offering relatives a cup of coffee (Rehnsfeldt et al., 2014).

According to Bailie and Gallagher (2012), dignity is not only the responsibility of professionals, but rather everybody's responsibility. They emphasize the staff's attitudes and the importance of what small things mean for people's dignity. They also emphasize the staff's responsibility to take care of their patients' dignity, which includes details such as how to offer an older woman from a certain social class tea or coffee in a cup without a saucer (Gallagher, 2008).

Former cancer patients claim that caregivers being more committed and offering "the little extra" such as holding patients hands and finding suitable clothing promotes their dignity, alleviating their suffering and made them feel valued. Offering this little extra is about a staff's willingness to share something with other human beings in interdependence (Arman & Rehnsfeldt 2007).

Women complaining about their treatment experience that the staff withheld explanations, and when they got an excuse from the health-care staff, the excuse was not from the person who treated them badly, which is something that increased their suffering and reduced their dignity. Their suffering could be described as a kind of double suffering, both as a result of their illness and also how they experience being met (Söderberg, Olsson, & Skär, 2012), with a similar result found in a study among men complaining about their treatment. They experienced being met with a disrespectful manner, physicians who doubted their symptoms, being treated with suspicion and having the wrong person apologize. If health-care professionals were sensitive and listened to their needs, the resultant experience could be one of dignity (Skär & Söderberg, 2012).

3 RATIONALE

The concept of dignity is emphasized in various contexts. From a human rights perspective, dignity is described as something inherent, which belongs to all human beings (UDHR, 1948). The Code of Ethics for Nurses (2012) says that it is a nurse's responsibility to alleviate patient suffering and to respect their dignity. Additionally, from a caring science perspective, this responsibility for taking care of other people is also emphasized. Previous research has shown that patients being admitted to psychiatric hospitals have expectations of being taken care of with dignity. Some patients have experienced being taken care of in a way that increases their dignity, but there are also patients who have experienced being met in a way that increases their suffering and reduces their dignity, with similar experiences being reported by relatives. The staff have reported both the importance of taking care of the patient's dignity, but also the challenges related to doing so.

The results from this study would be discussed towards a caring science perspective. From this perspective we all as humans are interdependent on each other, and that as human beings we all exert an influence on each other's life. For the individual human being, dignity is seen as a subjective experience, and by exploring the patients', the relatives' and the staff's experiences regarding taking care of the patients' dignity, this would make a contribution for professional carers in various aspects of taking care of the patient's dignity. Furthermore, all groups of patients, relatives and staff members would participate in this study. With this in mind, based on what the results from the independent studies explore, a deeper understanding for the participant's experiences would be revealed.

3.1 AIMS

The overall aim for this research was to explore patients', relatives' and staff members' views concerning patient dignity at mental health hospitals. The aims and purpose for each of the papers are:

- Paper I The aim of this study was to gain a deeper understanding of how the staff in a psychiatric hospital perceive the dignity in encounters with patients, and therefore to gain a better insight into the staff's perspectives and their understanding of the concept.
- Paper II The aim of this study is to gain a deeper understanding of the subjective experiences of patients in a psychiatric hospital with respect to dignity.
- Paper III The purpose of the present study is to reveal relatives' opinions regarding what is important for taking care of patients' dignity when they are admitted to a mental health hospital.
- Paper IV The aim of this study is to explore the experiences of patients and relatives in terms of how the dignity of patients is taken care of when they are admitted to psychiatric hospitals.

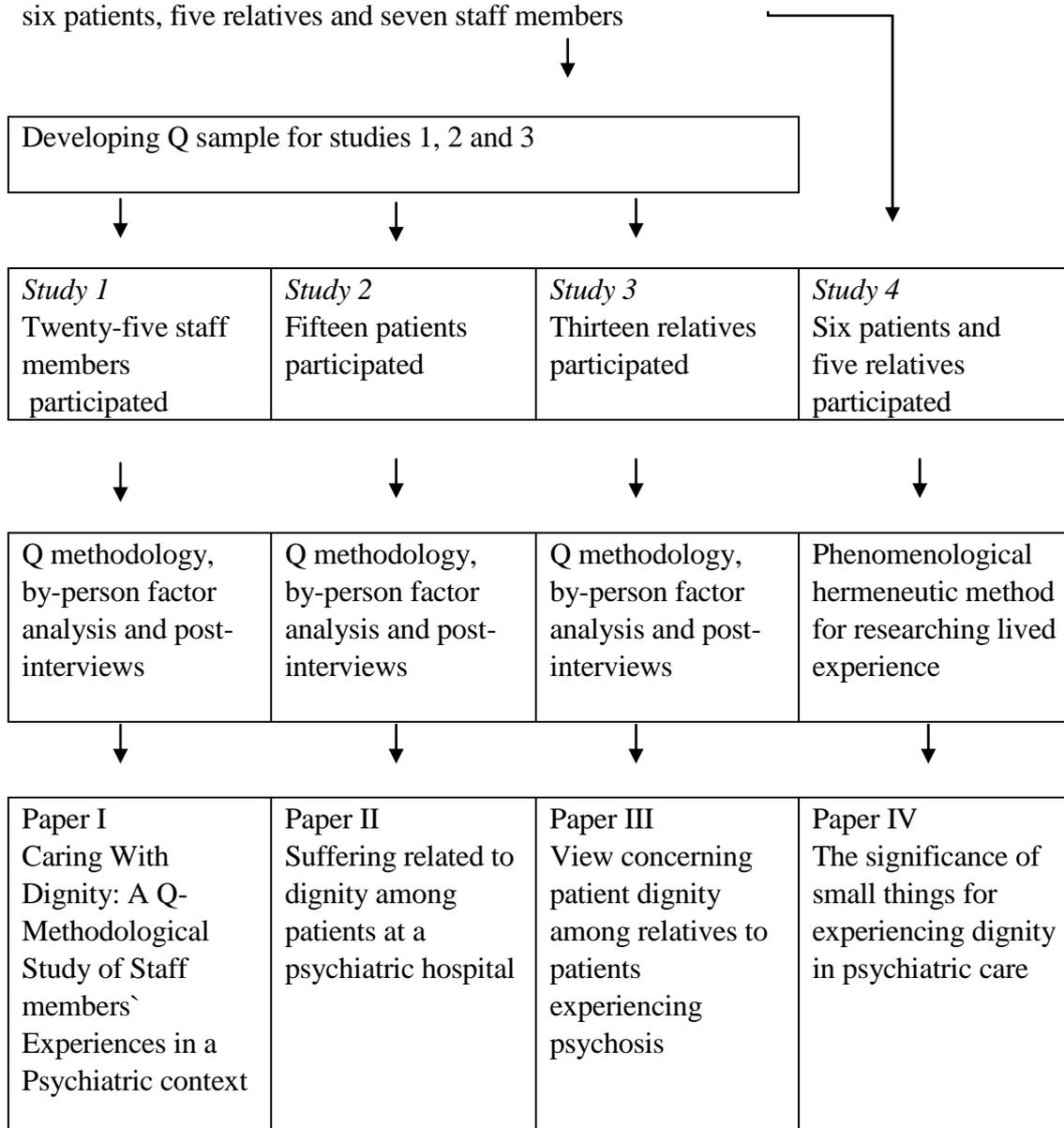
4 MATERIAL AND METHODS

Two different methodological approaches have been used for analysing the data collected for this thesis. In papers I, II and III, Q methodology was used as the methodological approach. In paper IV Phenomenological hermeneutic method for researching lived experience was applied. Most attention would be given Q methodology. Before presenting methodological approaches, the concepts of objectivity, subjectivity and abduction will be discussed.

4.1 OVERVIEW OF STUDIES

Figure 1. Overview of studies 1-4

Qualitative interviews with
six patients, five relatives and seven staff members



4.2 OBJECTIVITY AND SUBJECTIVITY

In both of the methodological approaches used in this thesis, the concepts of objectivity and subjectivity are worth reflecting upon. Objectivity, which can be understood as being inter-subjective and reproducible, can be seen in light of the empirical philosophical tradition, and in such a way that identical observations should be possible to be carried out by other persons at the same time, or by others under similar conditions later (Wulff, Pedersen, & Rosenberg, 1990). Based on ideals from natural science, reductionism is used as an approach to acquire more knowledge about the phenomenon or field one wants to study, and by studying the parts more knowledge is gained about the whole (Nortvedt & Grimen, 2004).

Subjectivities go the other way, and are about that all phenomena are interpreted uniquely by each individual. According to Stephenson (1978), subjectivity is about synthesizing so that each individual person's thoughts, feelings, observations, preferences, present experiences, past experiences, future expectations and so on are merged into a whole. All this and much more affect how that person interprets and understands what they are affected by. When talking about subjectivity, we are dealing with meanings and not facts (Stephenson, 1978).

4.3 DEDUCTION, INDUCTION AND ABDUCTION

In both natural science and human science, the logic behind methodological approaches is often described as deduction or induction. Deduction is based on some theoretical assumptions or hypotheses when studying a certain field by either testing or observing in order to discover whether these theoretical assumptions or hypotheses are strengthened or weakened. Induction goes the opposite way and starts with some observations such as statements or experiences, and based on this, one wants to generate or create more general statements or laws (Wulff, Pedersen, & Rosenberg, 1990). Abduction is a third maybe lesser known approach, and was introduced by the scientist Charles S. Peirce, who described abduction as a way to strengthen a cable by adding another line to the cable. The best possible explanation (a new line in the cable) contributes to one's understanding of the actual phenomenon (Johansson & Lynöe, 2008). By using the logic of abduction, one wants to explore and find meaningful deeper structures in the field of research (Råholm, 2010). Alvesson and Sköldberg (1994) describe abduction as a reflexive process of jumping between theory and empiricism, which is not about treating or testing observations. Observations are seen as signs of other things, while abduction is about creating applicable descriptions of a phenomenon in order to obtain new insights, find clues and follow the pursuit of an explanation (Watts & Stenner, 2012). Abduction can also be described as a form of qualified guessing:

Given, however, that it is impossible in advance to be absolutely certain what each clue means or is indicating, it becomes necessary to *guess*; or, if you want to express that more formally, to generate and explore a series

of likely hypotheses. These hypotheses can then be used as the basis for further empirical tests. (Watts & Stenner, 2012 p. 39)

4.4 Q METHODOLOGY

Q methodology was invented by the British scientist William Stephenson (1902 – 1989), and introduced in 1935. Q methodology was developed as an alternative to the prevailing scientific traditions, in which human behaviour, feelings and thoughts were reduced to objective measurements. Q methodology is described as a bridge between a qualitative and quantitative method that focuses on an individual's subjective experiences of phenomena (Brown, 1996). By using Q methodology, people's opinions, values, experiences, thoughts, attitudes, understandings, etc. were all looked upon from the perspective of each person's subjective, personal and unique world (Thorsen & Allgood, 2010). Its qualitative humanistic approach can be seen through its focus on a deep understanding, each individual participant's viewpoint and diversity among people. Q methodology's quantitative dimension is about a similarity among different groups of people identified by statistical analysis (Ellingsen, Størksen, & Stephens, 2010). By talking about operant subjectivity, Stephenson (1953) made it clear that a subjective phenomenon can be observed and studied under the same conditions as an objective phenomenon. With this meaning, subjectivity is not some type of mental process, but rather a behaviour that can be observed by its surroundings. A Q methodological approach can be described as a step-by-step approach, and in this presentation the steps will be presented in accordance with Brown's presentation (Brown, 1980).

Step 1- Concourse and statement collection: According to Brown (1993 p. 94), concourse can be understood as “the flow of communicability surrounding any topic” (from the Latin *concursum*, meaning “a running together”). In principle, a concourse on a theme is infinite, though at the same time easily recognized by the participants in a culture or context (Thorsen & Allgood, 2010). A concourse is often collected from both structured and unstructured interviews (McKeown & Thomas, 1988), but can also be collected from a wide range of sources such as newspapers, essays, talk shows (Brown, 1993), paintings, pictures, photographs, music (Stephenson, 1978) and illustrations (Størksen, Thorsen, Øverland, & Brown, 2012). Statements collected through interviews can be described as naturalistic (McKeown & Thomas, 1988). Stephenson emphasized that even if statements are collected from a wide range of communication, “it is not to be taken as a reductionist assumption” (Stephenson, 1978 p. 25). Instead, it is about exploring and finding an underlying understanding, and not a prediction and explanation (Stephenson, 1978).

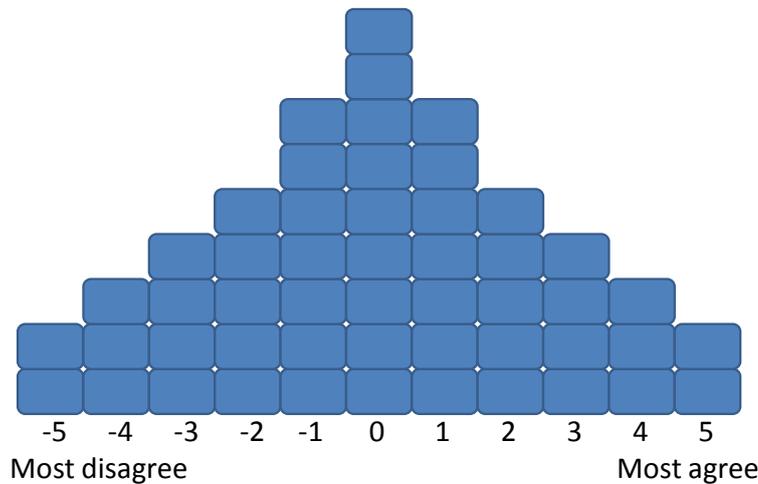
Step 2 – Q sample: The next step is to draw a sample of statements based on the concourse (all statements are from step 1). This Q sample, also called the Q – set, normally consists of 40-50 statements. But a Q sample may also consist of both less (Størksen et al., 2012) and more statements (Dziopa & Ahern, 2009). Furthermore, how one is extracting the statements from the concourse to the final Q sample is important since one wants to select a broad representative and balanced selection of statements from the concourse. Ideally, the amount of statements collected should be large enough

to draw a random sample from the universe of communication relevant to the topics one is studying (Kvalsund, 2010). Another way of doing it is to base the selection on some theoretical pre-understanding and by using some kind of balanced block design, securing to a higher degree the breadth of opinions relevant for what one is studying (Kvalsund, 2010; Brown, 1980). There is always a possibility that some of the opinions represented in the concourse would not be selected for use in the Q sample (Kvalsund, 2010; Brown, 1980). After the statements were selected they were printed onto individual cards.

Step 3 - P set: The P set is the group of the participating individuals who give feedback through the Q sample developed for the actual study. The selection of the P set should also secure a representativeness of the breadth and diversity among participants (Brown, 1980; Watts & Stenner, 2012). A strategic approach, insofar as selecting participants who represent a particular interest, is a legitimate way to recruit participants. But according to Watts and Stenner (2012), participants can be recruited through a kind of snowball sampling technique, with the number of participants differing compared to R methodology. In R methodology, large numbers of participants are needed in order to generalize from the participants to the population (Watts & Stenner, 2012). In Q methodology, the rationale and aim for the study are quite different, as it is not a question of statistical generalization from the participants to the population. By using Q methodology, the desire is to establish the existence of certain factors or viewpoints. This can be achieved using only a few participants (Watts & Stenner, 2012).

Step 4 - Q sorting: The participants responded to the Q sample developed in Step 2, and sorted statements in “the grid” (Figure 2) in accordance with the conditions of instruction. In this step, the statements are printed on individual cards and the participants place one card in each place in the grid (Figure 2) from -5 (most disagree) to +5 (most agree). It is possible to choose between a free choice distribution or a forced choice distribution, even if one prefers to use forced choice distribution in Q methodology. The purpose of free choice distribution is to let the participants choose the value of the available ranking numbers which they want to give each single statement by themselves. As the name indicates, forced choice distribution means letting the participants sort the statements in accordance with specific guidelines. The benefits of forced distribution are the highlighting of the psychological significance for the participant concerning the placement of statements on both the positive and negative side of the grid (Stephenson, 1953; Brown, 1980). In this study, the participants were instructed to sort the statements using a forced choice distribution. The shape of the distribution curve is not that important for the results, but what is important are the patterns of the statements within the distribution, which are relevant for the results (Watts & Stenner, 2012).

Figure 2. The Grid



After the participants have sorted the statements, is it possible to conduct post-interviews with them (Gallagher & Porock, 2010). Post-interviews can either be collected immediately after the participants have sorted the statements or later, though conducting the interview immediately after the statements are sorted can be timesaving for both the informant and the researcher. The participants' thoughts, beliefs and feelings are collected in present time, while an advantage of conducting post-interviews at a time agreed upon later can be that the participant would have time to reflect on their own thoughts and feelings, which could lead to deeper reflections relative to the topic. The rationale for doing the post-interviews is to "reveal underlying beliefs and values that lead to a particular stance" (Gallagher & Porock, 2010 p. 297). Alternatively, one could ask the participant to write down some comments relative to the statements.

Step 5- Q factor analyses: The data received from step 4 was analysed using a by-person factor analysis. Each participant's ranking of the statements was coded and allocated a unique number transferred to the grid (Figure 2). When using Q factor analyses, the focus is on each individual, and the factor loading indicates the degree of "like-mindedness" between individual people (Barker, 2008), which stands in contrast to a traditional factor analysis such as R factor analysis, in which one looks for a relationship between different variables (McKeown & Thomas, 1988). When performing a by-person factor analysis, the entire configuration of each Q sort was correlated and factor-analysed (Brown, 1980). By using statistical tools such as PQ Method 2.11 (Schmolck, 2002), which is designed for a Q factor analysis, it is possible to choose from among a Centroid Factor Analysis and a Principal Component Analysis (PCA). The next step is to rotate the factors. In Q methodology, one can choose between Varimax rotation and hand rotation. Varimax rotation is a mathematical method, the purpose of which is to maximize the saturation of the Q sorts on the factors extracted. When doing hand rotation saturation on each factor, the extracted data depends on the researcher's assessment of what the best way is of rotating it

(McKeown & Thomas, 1988). The strength of a correlation coefficient can be calculated and. By using the formula $SE_r = 1/\sqrt{N}$ “enables us to evaluate the strength of a correlation coefficient by comparing it to a theoretical situation where all is random (Brown 1980 p. 284). N is the number of statements. Loadings in excess of 2.58 (SE_r) is significant at the 0,01 level. Loadings excess of 1,96 (SE_r) is significant at the 0.05 level.

Step 6: Factor estimation: In Q methodology, the interpretation of the factors is primarily based on factor scores, which are “a kind of average of the scores given that statement by all of the q sorts associated by the factor” (Brown, 1993 p. 117). The factors scores are a result of each individual’s q sort representing the factor, which are weighted before they are merged into a single Q sort. The totality of the participants’ merged factor scores are visualized by what is called a factor array (Stenner, Watts & Worell, 2008).

Step 7: Factor interpretation: A factor interpretation is the last phase in doing a Q methodological study. When interpreting the results in Q methodology, one is interested in what the factor array as a whole communicates, and not what individual statements are communicating (Stenner et al., 2008). Each factor tells its own story through the essence of meaning, feelings, preferences, values and communicability from the negative pole through the more neutral area to the positive pole (Stephenson 1983a: 1983b) One way of doing this analysis is to start to emphasize statements with extreme scores on both the positive and negative sides of the grid (Figure 2), whereas the next step may be to look at distinguishing statements, which are statements that load statistically stronger on one factor compared to the others (Watts & Stenner, 2012). During the Q factor analysis, consensus statements, which are statements in which there is a high degree of agreement between the factors (or the viewpoints they represent) (Watts & Stenner, 2012), are also identified. It is important to uphold a holistic view concerning what the factor array as a whole communicates. As described by Ellingsen et al. (2010), one advantage with Q methodology is that to a greater degree the interpretation of the results is placed in the hands of the participants who have sorted the statements. In addition, by doing post-interviews, the participants’ underlying beliefs are revealed (Gallagher & Porock, 2010). This can also contribute to the interpretation process, as voices of the participants are heard to a larger extent together with the researchers’ understanding of the phenomena investigated.

4.5 VALIDITY AND RELIABILITY IN Q METHODOLOGY

In quantitative research such as that involving R methodology, there is always a question about validity and reliability. According to Brown (1980), the question about validity and reliability in Q methodology is not as relevant as it is when using other quantitative methodological approaches since each person is self-referential. Brown (1980) claims that because there is no external criterion for a person’s point of view, the issue of the validity of Q sorts is not applicable.

The reliability in Q methodology is also something different than the reliability in R methodology. By using the same Q sort, and doing repeated measurements of persons' viewpoints, one is testing to what degree one person's viewpoints is the same at one time as at another time. This kind of test/retest does not tell anything about the measurement scale; instead, it says something about the person doing the test. The type of reliability that could be relevant in Q methodology is called reliable schematics by Thomas and Baas (1992/1993). Reliable schematics is about when closely related groups of people are carrying out similar Q studies, and a degree of similarity among the various factors emerges. Moreover, there has been some test-retest reliability of Q sorts carried out, which has demonstrated reliability in a range from 0.80 upward (Brown, 1980).

4.6 PHENOMENOLOGICAL HERMENEUTICAL METHOD FOR RESEARCHING LIVED EXPERIENCE (STUDY 4)

The phenomenological hermeneutics method for researching lived experience was developed by Lindseth and Norberg (2004) with the purpose of exploring a health-care staff's (nurses and physicians) reasoning in ethically difficult situations, as well as getting people to talk about these situations, thereby exploring people's lived experiences in relation to this topic. According to Lindseth and Norberg (2004), and inspired by Husserl, the method is phenomenological in the way that it is focusing on lived experiences with the purpose of revealing the essence of lived experiences. An interpretation of the interview can be described as a hermeneutic process between parts and the whole. First, a naïve understanding of the text is presented, the text is divided into meaning units and those meaning units are then condensed into both sub-themes and themes. After this process of analysis, the entire text is read through for validating the naïve understanding and meaning units, and if necessary, the naïve understanding and/or meaning units are adjusted. Lastly, a comprehensive understanding is formulated. The process of interpreting the text can be described as a hermeneutics circle or hermeneutics spiral. By alternating between the whole text and parts of it, a new understanding arises and the essential meanings need to be revealed and interpreted throughout the text (Lindseth Norberg, 2004).

4.7 APPLYING THE METHODS IN THESE STUDIES

4.7.1 Recruiting participants

Five units at a psychiatric hospital were contacted for recruiting participants, and the inclusion criteria were as follows: For the patients, their mental status had manifested itself in the form of one or more psychotic episodes. "Relatives" were a patient's relatives or others that the patients defined as immediate family. In study 3 (paper III) relatives were recruited through a user organisation. "Staff members" included nursing assistants, nurses, mental health nurses, social workers, occupational therapists, untrained personnel, doctors and psychologists. The staff members worked on units

caring for patients with a history of psychotic episodes. More details about recruiting participants are presented in papers I-IV.

4.8 Q METHODOLOGY IN STUDY 1 - 3

Step 1 – Concourse and statement collection. Statement collection and identifying the concourse was done through qualitative interviews, each of which lasted from 50 to 150 minutes. Seven staff members, six patients and five relatives were interviewed face-to-face. The participant was asked the following question: When you hear a word like dignity, could you please tell me what you think about? The patients were further asked about what influenced their experience of dignity in being a patient at a psychiatric hospital. Relatives and staff members were given the same question, but were asked about what they thought influenced the patients' experience of dignity. All of the interviews except for two were taped and transcriptions were made, with a particular focus on getting the wording exactly right so that the subjects' viewpoints would come across clearly in the transcription. In one patient's and one relative's interview, the participants wanted their comments written down. Since the statements are taken from oral responses, they can be described as naturalistic (McKeown & Thomas, 1988).

Step 2 – Q sample: After transcribing the interviews, 1,751 statements relevant to the research topic were identified. As a starting point, the statements were grouped into 15 provisional categories, which are: primary statements, experiences, staff-patient encounters, situations, suffering, self-esteem, autonomy, staff competence and personality, attitude, understanding, time, relatives and important others, the health-care system, economy and medication.

In the process of reducing the statements to a number possible for the participants to handle, the main focus was to ensure that a breadth of views concerning the topic of the study was represented among the statements. The process of reducing the statements from 1,751 to 51 can to a certain degree be compared to a Delphi process (Polit & Beck, 2012). Several times, the statements were sent back and forth among the researchers, with focus on which statements should be retained.

Theoretically, based on a caring science perspective the statements were classified into categories such as ontological-, existential-, ethical- and caring-cultural statements. The statements were also divided into dignity preserving and dignity inhibitory statements. Ontological statements concern how we generally value ourselves and others as human beings (statements 1–12), existential statements about the self and the self-in-relation to others (statements 13–24), ethical statements focusing primarily on interpersonal relationships (statements 25–36) and caring-cultural statements (statements 37–48) concerning patient experiences within the health-care system. A miscellaneous category (statements 49–51) was also created, comprising three statements. It was also found that some statements can sometimes be placed under more than one category (Ellingsen et al., 2010).

The Q sample was then piloted by six colleagues of one of the researchers with the purpose of identifying statements that needed to be clarified and considered as being relevant or not. The time it took for the participants to sort the statements was also noted, and all statements were considered to be relevant for the purpose for which it was intended.

Step 3, the P-set was about selecting participants for studies 1 – 3. In study 1, the staff study (paper I), 25 staff members working at a mental health hospital participated. In study 2, the patient study (paper II), 15 patients participated. In study 3, the relatives study (paper III), 13 relatives participated. For more information about the inclusion and exclusion criteria and how the participants were recruited, see papers I, II and III.

Step 4, the Q sorting was about how the participants sorted the statements. In this study, a forced choice distribution was applied, while similar procedures for sorting the statements were also applied for all three Q methodological studies. The participants sorted the statements individually, and as a PhD student I was present during the process of sorting the statements. The participants were given specific information and instructions on how to sort the statements, with the conditions of the instructions for patients (paper II p. 151) as follows:

You will now be presented with 51 statements. All these statements contain a message relevant for your sense of dignity. Based on your experience, I would like you to order the statements from those you most agree with to those you most disagree with.

The conditions of the instructions for the participants in the staff study and relatives study were identical to those of the patient study, although the participants were asked to sort the statements relevant to the patient's experience of dignity (papers I and III). The participants were advised to first sort the cards into three piles, one for those statements they most agreed with, one for neutral statements and one for statements they most disagreed with. They were then asked to start sorting the statements in each of the piles, but the participants were also informed that it was quite in order to sort the statements in another way as long as it resulted in that all the spaces in the distribution grid (Figure 2) were filled up. By instructing the participants to sort the statements, and placing one card in each place in the grid (Figure 2), the participants were forced to prioritize between the statements. The participants were also informed that they could switch places and change the ranking of the cards as many times as they wanted, and that there was no right or wrong answers since the researchers were interested in the participants' individual subjective opinions. But as the name indicates, the participants were forced to put one card in each place in the grid (Figure 2). Additionally, the grid was drafted on a large portable oilcloth, and each of the 51 cards was laminated.

Since the researcher met and instructed each participant during the process of sorting the statements, it was possible to both answer potential questions and respond to potential thoughts and reactions from the participants. The sorting of the statements for patients was done at hospital wards, with the exception of one patient who wanted to respond to the study in his/her home. Relatives sorted the statements at one of the researchers' workplace or at relatives' homes, while staff members sorted the

statements at the ward they were employed at. Post-interviews were performed immediately after the participants had sorted the statements, and the participants were asked to comment on why they placed some statements under “most agree with” (+5, +4, +3) and some statements under “most disagree with” (-5, -4, -3). They were also asked if they wanted to add other comments.

Step 5 Q factor analysis, Step 6, factor estimation, and Step 7, interpretation: The analysis of the data was done by using the PQ Method software programme (Schmolck, 2002), and by a person factor analysis, which was conducted in the patient-, relatives- and staff studies (papers I- III). By using the formula $SE_r = 1/\sqrt{N}$, loadings in excess of 2.58 ($SE_r = +/- 0,361$) is significant at the 0,01 level. Loadings excess of 1,96 ($SE_r = +/- 0.274$) is significant at the 0.05 level. More details about the analysis and interpretation of each individual study are presented in papers I-III.

4.9 PHENOMENOLOGICAL HERMENEUTICAL METHOD FOR RESEARCHING LIVED EXPERIENCE IN STUDY 4

This study is based on qualitative interviews conducted with six patients at a psychiatric hospital and five relatives of patients with a mental illness. The interviews among patients and relatives are the same as those collected for the purpose of identifying concourse for studies 1–3 (see pt 4.4 Step 1 – Concourse and statement collection page 18, and pt 4.8 Step 1 – Concourse and statement collection page 23). In this study, we followed the steps described by Lindseth and Norberg (2004) to help analyse what patients and relatives communicated through the qualitative interviews, though this process of analysis was not a one-way linear process. First, the interviews were read several times, and the formulating of the naïve reading was also done several times before we went on to formulate the sub-themes and theme. This way of analysing the interviews was applied for all the steps of the naïve reading, the formulating of the sub-themes and themes, and the formulating of a comprehensive understanding. The comprehensive understanding, themes and sub-themes were also validated in relation to the naïve reading.

4.10 ETHICAL CONSIDERATIONS

Before we started collecting data for these studies, the necessary approvals were applied for. A description of the project, an example of the information letter and the written consent for all the various groups of patients, relatives and staff members were sent to The Regional Committee for Medical Research Ethics in Western Norway, and the same information was also sent to the Norwegian Data Protection Agency with information about how to protect the participants' confidentiality. Both the Regional Committee for Medical Research Ethics in Western Norway (reg. no. 2008/13776 CAG) and the Norwegian Data Protection Agency (reg. no. 20522/2) approved the study. After receiving the approvals, we asked the psychiatric hospital about obtaining

permission to include wards at the hospital in the study. Finally, after also receiving approval from the hospital, we started collecting data.

All of the participants in the studies were given written and oral information about the study, including what theme we wanted to study, the aim of the study, the procedure for collecting information from the participants and an analysis of the data. The written information also informed them about their rights to withdraw from the study at any time, as well as their right to withdraw their consent at any time they wanted, and all the participants were also informed about how their confidentiality would be protected, which was done by assigning code numbers. Their written consent and the collected data were stored separately in locked boxes in separate buildings at the university college.

In study 3 (paper III) among relatives, we initially wanted to recruit relatives through the psychiatric hospital from where the patients and staff members had participated. After some discussion in the research group, we decided to recruit relatives through a user organization. The Regional Committee for Medical Research Ethics in Western Norway approved the amendment in the process of recruiting relatives to participate in the study (reg. no. 2011/55-2).

In the qualitative study (paper IV), the analysis is based on qualitative interviews with patients and relatives, which was primarily collected with the purpose of identifying the discourse and developing the Q sample for studies 1–3 (papers I-III). Before the participants were interviewed, we informed them that we also wanted to do a qualitative analysis of the interviews. Information about this was also sent to the Regional Committee for Medical Research Ethics in Western Norway.

An ethical dilemma could be that the patients and relatives are sometimes in a vulnerable position as a consequence of the patients' illness. With the purpose of avoiding any increase in the patients' suffering, before the patients were asked to participate in the study, the recruiting of patients was approved by the ward nurse at all the wards at the psychiatric hospital. The researcher, who is also a trained mental health nurse, was also present together with each patient and their relatives during the data collecting period, which is something that could secure their situation. As an overall impression, both the patients and relatives communicated that they found the study to be important, and agreed to participate in the study.

5 RESULTS

Table 1. Summary of the results

Paper I	Paper II	Paper III	Paper IV
<i>Partisipants:</i> 25 staff members participated	<i>Partisipants:</i> 15 patients participated	<i>Partisipants:</i> 13 relatives participated	<i>Partisipants:</i> Six patients and 5 relatives participated
<i>Analysis:</i> Principal component factor analysis with varimax rotation <i>Results:</i> 10 staff members loaded significantly on one of the factors 15 staff members loaded significantly on both factors and were excluded from further analysis. Correlation between the factors was relatively high ($r = 0,42$)	<i>Analysis:</i> Principal component factor analysis with varimax rotation and hand rotation <i>Results:</i> 15 patients loaded significantly on one of the factors Correlation between the factors was relatively low ($r > 0.38$)	<i>Analysis:</i> Principal component factor analysis with varimax rotation <i>Results:</i> 11 relatives loaded significantly on one of the factors 2 relatives loaded significantly on two factors and were excluded from further analysis. Correlation between the factors was low ($r > 0.35$)	<i>Main theme:</i> 'The significance of small things for experiencing dignity' <i>Subtheme:</i> 'To be conscious of small things' 'Being conscious of what one says'
Viewpoint 1 (7 staff members) 'Patient focused staff' Viewpoint 2 (3 staff members) 'Challenges for staff'	Viewpoint 1 (5 patients) 'Being met as equal human beings' Viewpoint 2 (3 patients) 'Experience of dignity despite suffering' Viewpoint 3 (4 patients) 'Suffering due to feeling inferior' Viewpoint 4 (3 patients) 'Suffering and fighting for one`s own dignity'	Viewpoint 1 (3 relatives) 'Value based' Viewpoint 2 (4 relatives) 'Expectations' Viewpoint 3 (2 relatives) 'Asymmetry' Viewpoint 4 (2 relatives) 'Nuanced'	'Being met' 'To be aware of personal chemistry'

In the following section, the results of the papers included in this PhD thesis will be presented. Papers I, II, and III were done using Q methodological approaches, whereas paper IV, which is based on qualitative interviews done with patients and relatives, was done using a phenomenological hermeneutics approach (Figure 1).

5.1 STUDY 1, PAPER I

Seven staff members defined viewpoint 1, the 'Patient focused staff'. They communicated the importance of respecting people's uniqueness, treating them as equals and being aware of the patient's vulnerability. These staff members emphasized qualities such as being honest and behaving in a manner that makes it possible for patients to trust and feel safe with the staff. They disagreed about that deep inside we as human beings are inviolable, and also disagreed that being given a diagnosis meant nothing for the patients. They also disagreed about critical statements regarding the staff and the health-care system, e.g. that the patients could not complain about the treatment, that the staff were nice but superficial, or that the patients were sent from pillar to post.

Viewpoint 2, 'Challenges for staff', is defined by three staff members. They also flagged equality and a respect for people's uniqueness as being important. However, the focus seems more to be on their own challenges, such as how the staff should behave, e.g. asking the patient how they feel, creating a good atmosphere, ensuring that the patients are able to trust and feel safe with the staff, being knowledgeable, being there for the patients to talk to and listening to the patients. Challenges such as how their own previous experience influenced the present situation was communicated through post-interviews, but at the same time they disagreed regarding critical statements such as it did not help to complain, and that the staff exercised authority. They either did not find the staff to be superficial or that the patients were treated as if they were on a production line. Generally speaking, the staff seemed to communicate that they took the patients seriously and treated them well. But as one staff member said, patients experienced that they might be different, and that his (staff's) way of understanding it could be a form of self-defence.

5.2 STUDY 2, PAPER II

Paper II is about the patients' experiences. The five patients defining viewpoint 1, 'Being met as an equal human being', communicate the importance of trust and feeling safe with the staff, and that the staff listened to them, took them seriously, treated them as being equally valuable and believed in their potential. Staff qualities such as their knowledge levels and managerial attitudes were also important. They disagreed about critical statements such as the staff exercising authority, that the staff thought the patients did not know what was in their own best interest, that they were treated as if they were on a conveyor belt or that user participation did not exist. Furthermore, they also disagreed that we as human beings are inviolable deep inside.

Two patients defined viewpoint 2, 'Experience of dignity despite suffering'. They said that we are all innately inviolable and equally valuable, and that their own experiences increased their respect for others. They also found that unpleasant actions such as coercion and taking medicine were sometimes necessary. But if the staff did not value them as they are, they would not be able to value themselves, in addition to that not being able to talk with others about one's illness increasing one's suffering. Nonetheless, they disagreed regarding critical statements against the staff, such as that the staff was superficial or that the staff said that the patients did not know what was in their own best interest. They either did not experience any time pressure, or that there was no user participation. They also did not agree that being given a diagnosis meant nothing, or that sometimes something good could come from being violated.

Four patients defined viewpoint 3, 'Suffering due to inferior feelings'. They emphasized the importance of being seen as being equally valuable, that the staff should listen to- and be honest with them and behave so that the patients were able to trust the staff. But they experienced being patronized, and that the staff did not think that they knew what was in their own best interest. Vulnerability was also communicated and they disagreed that we are all inviolable deep inside, that the experience of being violated could be a wake-up call or that being given a diagnosis meant nothing. They also disagreed that one could find comfort and peace in one's faith or that money had no impact on their own experience of dignity.

Viewpoint 4: 'Suffering and fighting for one's own dignity' is defined by three patients. They find humour to be important, and that we are all equal and have the potential to make our situation better. But they mean that patient's intrinsic dignity can be trampled in the health-care system, that a manager's attitude exerts an influence and that staff members may unconsciously exercise authority. They also found the staff's knowledge to be of importance, and that the use of medication was sometimes necessary. But they disagreed about whether it was the nursing staff they talked to or that it was isolating not being able to talk with others about their own illness. One patient said that he had nothing to talk about with the staff since they evaluated everything the patients and staff talked about, and that the staff's use of coercion was a negative influence. Despite this, they did not experience any time pressure and they also experience user involvement.

5.3 STUDY 3, PAPER III

Three relatives defined viewpoint 1, 'Value based', including values such as honesty, seeing the unique individual irrespective of a diagnosis and treating them equally whatever the condition or what they have done. One should also take other people's opinions seriously, and accept that they do not feel the same as oneself. But patients also risked losing their intrinsic dignity, and could experience being trampled on within the health-care system. Sometimes, one also could feel forced, which exerted a negative influence on one's dignity. But they did not experience that the staff was superficial, or that the staff exercised authority in a way that indicated that they knew better than the

patients. It was not only the nursing staff they contacted if there was something to talk about. They did not find us as human beings to be inviolable deep inside.

Viewpoint 2, 'Expectations', was defined by four relatives. They communicated the importance of involving relatives, not only for the sake of the relatives, but as one of them said, they had important information about the patient's condition. They stressed the importance of being asked about situation, and also perceived not being able to talk with others about the patients' illnesses as an isolating experience. Additionally, they also emphasized respecting people's uniqueness and that we are all equally valuable, while encounters with mental health services also increased their respect for any differences. Staff behavior, such as valuing the patients, the atmosphere of a ward and the manager's attitude all influence how patients value themselves. They disagreed that deep down we all are inviolable or that patients being given a diagnosis meant nothing. At the same time, they disagreed with the notion that no one asks the patients, that there is no user participation and that it is difficult to complain about treatment.

Viewpoint 3, 'Asymmetric', is defined by two relatives. They say that we all are equally valuable, with the potential to change, and make things better. To treat everyone alike does not necessarily address individual dignity, as well as the degree that patients feel safe and trust the staff does influence the patient's situation. But they did say that the staff unconsciously exercises authority, that the patients are shuffled here and there as if they were on a conveyor belt, that the staff should talk normally to patients and that professional knowledge and user participation should be equally valuable. Also, they felt that relatives should be included to a greater extent in the patient's treatment, and that patients' dignity could be taken away, though it depended on how strong one's dignity is, or how vulnerable one was as a patient. They disagreed that we were all inviolable deep down as human beings, that being given a diagnosis meant nothing for the patients, or that the patients could find comfort and peace in their faith. They also disagreed that it is not possible to complain about one's treatment. Worth noting is that they disagreed that it is important that someone /staff asked the patients how they feel. One relative explained it like this: "In difficult situations, it is okay that people ask [patients], but when they're feeling better it could be a reminder of their problems."

Two relatives defined viewpoint 4, which communicated a more 'nuanced' view. They understood the need for using both medication and coercion in patient care, with one relative describing how the patient he was related to had learned through experience why he needed medication. They emphasized the responsibility of managers and individual staff members, such as that the staff appreciated the patients when they were ill, that the staff took the patients' opinions seriously. They also said that we are all equally valuable, and by the recognition of others' dignity, then both parts are affected. They found the staff's personality to be important, and that some staff patronized the patients without knowing that they were doing it. They disagreed about whether it is degrading to not look well. They also did not agree with the idea that human beings are intrinsically inviolable, that human beings are equally valuable no matter what they have done, or that the experience of violating can be a wake-up call that resulted in something good. They did not find the staff to be superficial, that the patients were treated as if they were on a conveyor belt or that there was no user participation.

5.4 STUDY 4, PAPER IV

This paper explores the experiences of patients and relatives to patients in terms of how the dignity of patients is taken care of when they are admitted to psychiatric hospitals. All of the participants was asked to explore their own thoughts related to the concept of dignity, and they were also asked about saying something about what they believed would increase and decrease a patient's dignity. Even if relatives were asked about what influenced the patients' experience of dignity, they also reflected on how their experiences regarding patients had been taken care of by the mental health-care system with regard to influencing their own dignity. The analysis revealed one main theme and four sub-themes (Table 1, paper IV). The main theme was given the name: 'The significance of small things for experiencing dignity'. As described in the sub-themes, this is about being conscious of small things. It is also about being conscious of what one says, how one is being met and about personal chemistry. One way of understanding this could be that the hospital staff members do not give enough attention to the importance of these small things. What are extraordinary situations for patients and relatives are ordinary daily situations for staff members, and staff members need to explore this phenomenon systematically and expand their own understanding of it.

6 DISCUSSION

In the subsequent discussion, the studies will be discussed as a whole. Since the same Q sample was used in all three Q methodology studies, it would be possible to do a second-order factor analysis based on how patients, relatives and staff sorted out the statements in the grid (Figure 2). This discussion is not based on a second-order factor analysis, but rather on what the various studies convey. The four studies reveal various forms of experiences, but what they all have in common is that they convey the importance of staff for patients' experience of dignity. Dignity increasing experiences, such as the importance of having overarching values in the encounter between the patient and staff, also suggest that patients are taken care of by the staff. However, both patients and relatives communicate also other experiences. The experiences communicated by patients and relatives, and also to some degree the staff, are about that the encounter between the patients and staff has its challenges. This concerns a relationship between parts that are not equal, as well as to what extent the staff is conscious of their responsibility towards the patients

Three different themes will be discussed, which are:

- Dignity as a result of caring
- Suffering and reconciliation
- Compassion a way of communicating ones ethos

6.1 DIGNITY AS A RESULT OF CARING

Values such as equality and respect for the uniqueness of all human beings are what the participants in the staff study (viewpoints 1 and 2), the patient study (viewpoint 1) and the relatives study (viewpoints 1 and 2) are in the most agreement about. One way of understanding this is that there are some overarching values among the participants that define the factors that are of significant importance for them (Brown, 1980; Stephenson, 1953). The importance of respecting them as human beings and treating them as equals was also found in a study by Schroder et al. (2006) and Schroder et al. (2007). The fact that patients, relatives and staff rank these values among what they are most in agreement about is important. Eriksson (Lindström et al., 2010) describes ethical caring as what we do in practice through our approach in our meeting with the individual patient. As human beings, whether we are conscious of it or not, our values are fundamental with regard to how we meet other people, whereas how we act towards other people reflects our ethos.

The participants also seem also to have expectations regarding the staff's behaviour. They seem also as a whole to be in disagreement regarding critical statements toward the staff's behaviour, such that that the staff are superficial, or treat patients as if they're on a production line (paper I, viewpoint 2). One way of understanding this is that they experience patients being cared for by staff in an ethical way. Lilja and Hellzen (2008) refer to some situations as dignity promoting experiences when the staff treat them like

normal human beings. These situations are described as light in the darkness (Lilja and Hellzen, 2008).

These papers (paper I-III) communicate that there are some expectations, or in Løgstrup's (1997) words, a demand that is given to the staff to take care of the patients. This demand is given to them from not only the patients and relatives, but also from the staff themselves. As with ethos (Eriksson, 2003), the ethical demand (Løgstrup, 1997) cannot be only rules, as it is beyond rules, it is an integrated part of carers' way of being towards patients. Løgstrup (1997) also talks about a silent ethical demand. One way of making people conscious of this demand towards other people is to put some flashlights (Austin, 2003) on ideals and goals for caring. Ideals, such as taking care of patients' dignity can then be prerequisites for actions (Jacobs, 2001). It is also interesting to look at what patients and relatives communicated in paper IV, and important for their experience of dignity was that the staff should: "Behave decently... be normal..., say good morning... she [the staff member] did not say many words..., and she [the staff member] was human as she should be (paper IV). One of the relatives also said that the staff do not need to say so much; instead, what was important was what they said.

What these participants communicate, and also what earlier research has shown in (Gustafsson et al., 2013; Rehnsfeldt et al., 2014; Baillie & Gallagher 2012; Gallagher 2008; Arman & Rehnsfeldt 2007) can be seen in light of Eriksson's words that, "the act of caring is the art of making something special out of something less special" (Lindström et al., 2010). As described in paper IV, it is important for staff members to be aware of what patients and relatives recognize as dignity promoting behaviour, which can be described as an ethical caring approach, in relation to the staff respecting them and confirming their uniqueness as human beings. As communicated by patients and relatives, an ethical caring approach is also about being aware of these ordinary details in each unique meeting between patients, relatives and staff. As suggested by service users in a study by Brimblecombe et al. (2007), some carers at all wards should be given the role of being "modern matrons". The main task of these modern matrons may then be to maintain attention on what is one's unifying goals for taking care of the patient's dignity, but also to put flashlights (Austin et al., 2003) on what the challenges are. Maybe staff in mental health care should also invest in some type of "magnifying glasses" for studying details in their everyday meeting with patients to help be more aware of these small things.

6.2 SUFFERING AND RECONCILIATION

As discussed above, some participants are experiencing patients being taken care of in a way that takes care of their dignity. But there are also patients and relatives who communicate the opposite. In both the patient- (paper II, viewpoints 3 and 4) and relatives studies (paper III, viewpoint 3), some participants experienced a kind of imbalance in the relationship between patients and staff, something which increased their suffering. One way to describe what patients and relatives are communicating here is that this imbalance between the parts results in the patients not being met by the staff in an ethical way. In accordance with a caring science perspective, suffering is an

inseparable part of human existence, and suffering and health are each other's prerequisites (Lindström et al., 2010). But in accordance with Eriksson (2006), suffering and a reduced dignity for patients can also be a consequences of how they experience being met by the staff, which is also similarly described by Jacobson (2009, 2012). That patients and relatives still report these experiences is both surprising and not surprising, though it is not surprising since it is well-documented historically (Foucault, 1973). Other studies have also described this imbalance and dissatisfaction with regard to how patients, and also relatives, are being met in the health-care system as a whole (Bramesfeld et al., 2007; Svedberg et al., 2003; Hagen & Nixon, 2011b; Weimand et al., 2011; Pejler, 2001; Saunders, 2003). Söderberg, Olsson and Skär (2012) described not being met by staff in a good way as a kind of double suffering, which reduced their experience of dignity. Similar is found in a study by Skär and Söderberg (2012). But it is surprising because of developments that have taken place over the past 20 years within society with a focus on this imbalance, with user participation and formal rights for users (Social and Health Services in Norway, 2006) hopefully resulting in a more balanced relationship between patients and the health-care staff.

There seems to be several ways to understand why some patients and relatives experience the relationship toward patients as being non-ethical. This is something which also to some degree is discussed in papers I, II and III. It can be a form of self-defence from the perspective of staff, who whether they choose to be conscious of it or not, tend to not see the suffering of the individual human being, as described by (Travelbee, 1996). Nevertheless, one relative commented that the staff does not see the patient as an individual, with Wilhelmsson (2011) describing something similar in talking about discontinuity, inconsistency, distrust and a lack of empathy on the part of the staff. This can be understood in a way so that the staff, which is in a position of defining how the patient should be taken care of, can decide whether or not to see the patient as an individual. But as described by Wilhelmsson (2011), it is also worth noting that the same relatives had also experienced good meetings and a glimmer of hope in the relationship with the health-care staff. In these caring encounters, patients and families are those who are in a position of vulnerability, with the staff being the ones in position to increase or decrease their dignity.

Another way of understanding what patients and relatives communicate is that they experience that the staff do not respond to the trust given to them by the staff. According to Løgstrup (1997), trust is a sovereign expression of life, something that we as humans are born with. We meet other people with trust until we experience the opposite of it often enough. One patient says (paper II, viewpoint 4) that he chose not to talk to the staff about his situation since the staff reports on- and evaluates everything he says. A situation like this is about distrust, which is the opposite of trust. Something familiar is found by Eriksen (2012), who describes service users as being in a vulnerable position, struggling to be recognized. There are also times when service users choose not to say anything at all, since they do not want to let the professionals be the ones to define the situation. In accordance with Løgstrup (1997, p. 28), it is only by using the metaphor "holding another person's life in one's hand" emotional power is released. The emotions in the metaphor grow out of the fact that we have the power to determine something in the other person's life.

In paper IV, patients and relatives emphasize the importance of these small things. One relative said that, "I think that they [staff members] have forgotten these small details...". One patient used as an example a situation when staff members outside the hospital forgot to remove their identification card." As discussed in paper IV, these kinds of situations can be described as details or small things, which according to Jacobson (2009), can also be described as the violation of dignity on a micro level. Løgstrup (1997) says that if trust is being met by another kind of reaction other than trust, it turns into distrust. Distrust can be a result of indifference, reservation and rejection, and these dignity violating ways of meeting patients by staff members can be described as non-ethical. One could also ask why the staff are not doing what they know they should have done. As discussed in papers II and III, human beings have a tendency to not always act in accordance with what is best for other persons, even if they know what they should have done. Løgstrup (1997) explains this by saying that we do not want to be disturbed in our convenience. One way of interpreting what patients and relatives communicate is that the staff, whether consciously or unconsciously, does not take the responsibility given to them to take care of a human being who is suffering.

There are also some participants who communicate suffering, but who also seem to find a kind of meaning in their experiences. Both patients (paper II, viewpoint 2) and relatives (paper III, viewpoint 4) communicate some common experiences, although there are aspects that differentiate them. In both studies, they find patients in a vulnerable situation, and that nothing good has ever come from violating a patient's dignity. Also worth noticing is that they sometimes found the use of coercion and the use of medication necessary. Previous research has described how the use of coercion leads to a reduction in patient dignity (Hagen & Nixon, 2011; Kogstad, 2009). But among the participants in the post-interviews (paper II, viewpoint 2; paper III, viewpoint 4), some of them explained that in retrospect they had seen the necessity as to why coercion was used. Morse (2001), Eriksson (2006) and Rehnsfeldt and Eriksson (2004) all describe humans experiences of suffering as a process and how it is possible, based on one's experiences, to find reconciliation and new insight into one's life. Morse (2001) describes this process as a reformulation of the self. Eriksson (2006) talk about reconciliation, which opens up for creating a new wholeness or holiness, which is something that also includes one's negative experiences. The person who has gone through the drama of suffering often finds meaning in these experiences. Rehnsfeldt and Eriksson (2004) describe these experiences as being meaning creating in a communion in the struggle of suffering. Rehnsfeldt and Eriksson (2004) also talk about the importance that there is someone, carers together with the suffering human being, who can alleviate the patient's suffering. In these studies (papers II and III), the participants communicate the importance of how to be met by the staff. As described by the authors above, one's experience of suffering can be understood as a process, and since to some degree they have gone through the process of reconciliation and a new understanding of the present situation has arisen, the participant's life is not dominated by suffering to the same degree. As a result, patients, and also relatives seem to have reached a position of looking at their own situation from more than one side.

6.3 COMPASION A WAY OF COMMUNICATING ONES ETHOS

As discussed above, the relationship between the patients towards the staff are emphasized as being of major importance in all four studies. It is communicated that not only as a professional carer, but also as a fellow human being, it is the staff's responsibility to ensure that the patient's dignity is maintained. But challenges in the relationship between the patients and staff have also been pointed to in these studies. This does not mean that all patient suffering is a result of how they are being met by staff, but as previously discussed, some of the patients' suffering and the experience of reduced dignity can be a result of how patients and relatives are being met by the staff. An awareness of this was discussed to some degree in study 1, viewpoint 2, "Challenges for Staff", in which the staff's capacity for having a critical self-reflection was also emphasized as important for taking care of the patients' dignity. Wiklund Gustin and Wagner (2013) discuss how self-compassion, which includes an awareness of how one's own reaction towards a patient's situation makes it easier for the staff to understand and deal with other human beings, which is something that can be a source for compassionate care.

Wiklund Gustin and Wagner (2013) talk metaphorically about, "The butterfly effect of caring". This is about how small things in the moment can create a huge influence or change later, which is something about how important it is to have a focus on the here-and-now in every encounter between patients and carers. Wiklund Gustin and Wagner (2013) also refer to Arman and Rehnsfeldt (2007), describing caregivers' willingness to give "the little extra" as a symbolic act for caregivers to connect themselves to the suffering of others. What in study 4 (paper IV) is described as, "The significance of small things", can also be seen as a way for staff to connect themselves to the individual patient. It can be seen as some kind of symbolic act towards the patient, but can also be a kind of symbolic act towards themselves as carers. It is a way for the staff to be present in the moment together with the individual patient. The staff needs to be aware of this, and the staff needs to be willing to be there for the patient as a fellow human being. But as discussed by Hem and Heggen (2004), it is a huge responsibility for a staff to communicate compassion towards patients, as a staff will violate a patient's dignity if they communicate compassion without taking the patient's signals seriously. An awareness of vulnerability in situations together with patients can be a way for a staff to understand, recognize and prioritize being there for patients when they are vulnerable, while also preserving their human dignity. By becoming and belonging together with patients, we open up for the possibility of both a patient's- and our own vulnerability (Wiklund Gustin & Wagner, 2013).

Rehnsfeldt (et al. 2014) discusses the importance of integrating an ethos in both the caring culture organization and in each individual caregiver. Rehnsfeldt (2014) also claims that both an ethical- and non-ethical caring context can exist side by side, and that this is a question about to what degree this ethos is integrated in both each individual carer and in the culture as whole. That some patients and relatives experience a staff's behaviour in a way that results in increased suffering can be a result of that they experience being met in a non-compassionate way, or that the staff have lost or are not conscious of their ethos. But it is also worth keeping in mind that some

patients and relatives describe situations in which they experience that the staff is aware of these small things (paper IV), in addition to viewpoints communicating that they experienced that the staff met them as equal human beings (paper II), with a focus on values (paper III). In accordance with Eriksson (2003), ethos is both an ontology and an inner “should”, rather than being a question about some rules on how to act, or as a way of telling people to behave in a certain way. Being aware of one’s own challenges between the patients, relatives and staff opens up for letting ethos, the inner moral compass, to guide us in our unique meeting between patients and staff. An awareness of the small things can be symbolic acts for staff both towards patients and relatives, but also towards themselves. This is a way for the staff to be able to meet patients in a compassionate way, something which reduce patients’ suffering, which honour the patients- and staffs’ own values.

6.4 IMPLICATIONS FOR PRACTICE

Based on the results of papers I – IV, the following suggestions for taking care of a patient’s dignity while being patient at a psychiatric ward can be made. The importance of putting dignity on the agenda among staff members has been shown in all four papers. As suggested in paper II, the staff’s attention should also be as much on how they are doing things as what they are doing. One can also add that the staff should have a focus on why they are doing things, which may be the most important part of a staff’s professional awareness.

Also as suggested in paper I, the importance of developing critical thinking among individual staff members, including being an integrated part of a ward’s prevailing caring culture is also important. A staff needs to be aware of what increases a patient’s experience of dignity, but also what reduces their experience of dignity.

At each ward the importance of having a focus on overarching values, as well as its practical implications at the ward, should systematically be put on the agenda among carers. Concepts such as dignity should also be explored and discussed among the staff.

By integrating compassionate care as a part of a carer’s ethos, ethical caring can be visible through the way the staff behave towards patients. Integrating compassionate care can also be a way for carers to not lose perspective on who is in focus, namely the patients, in addition to the relatives’ experiences.

The staff also needs to keep their attention on what they can look at as small things or routines in their encounters with patients and relatives. Being in a vulnerable position as a patient or a relative, small things are of major importance for their experience of dignity.

The staff also needs to establish routines for integrating relatives into the caring of patients. By listening to relatives, a staff’s understanding of a patient’s situation will increase. Another side of it is that even if the focus is on the patient’s situation, the

relatives also have their own needs, and by offering the relatives time, listening to them and taking them seriously, their suffering can be alleviated and the experiencing of dignity will be increased.

A mental health care staff need to be aware that being a patient at a psychiatric hospital is about being dependent on carers. The importance of being aware of this is that not only some patients, but also some relatives, still experience suffering and vulnerability as a result of the staff's way of being towards them. Focus on suffering, why patients experience suffering and its consequence for patient's experience of dignity need to be a part of staff member's self-critical thinking.

Some advice could be that at each ward, some staff should have a role as modern matrons. These matrons could then be a positive enabler in a way so that all staff members as an integrated part of their professional ethics use, metaphorically speaking, flashlights to keep the attention on taking care of patient's dignity, i.e. being hammers for defending and protecting a patient's dignity, and to use magnifying glasses for focusing on the small things in their everyday meeting with patients. The staff could also maybe use some kind of mirrors so that they always could observe their own ways of being towards patients. The staff needs to be aware that each and every one of them can make a difference in a patient's experience of dignity.

7 METHODOLOGICAL CONSIDERATIONS

Q methodology and the phenomenological hermeneutics method represent two different ways of studying people's experiences, but both methodological approaches can be understood as methods which explore the topic under investigation. When using Q methodology, one views subjectivity as something operant that can be observed as behaviour. The phenomenological hermeneutics method represents a process of achieving insight into people's interviewed life world, and some considerations relative to both approaches will be discussed.

7.1 METHODOLOGICAL CONSIDERATIONS RELATIVE TO Q METHODOLOGY

As described by Watts and Stenner (2012), Q methodology is about studying people's subjectivity as something operant. With that in mind, some considerations with regard to the statements are worth some reflections. The statements in the Q sample collected to use in studies 1–3 can be described as naturalistic statements that sometime make it difficult to interpret them (McKeown & Thomas, 1988). Watts and Stenner (2012) describe some challenges, particularly in relation to whether one uses naturalistic statements, and give some recommendations for developing the Q sample. One piece of advice is to keep the statements as natural as possible even if there are no absolute rules, especially if the researcher(s) has special expertise in the field (Watts & Stenner, 2012). The subsequent discussion will elaborate that some statements in the Q sample developed for use in studies 1–3 can be difficult to interpret. Negatively expressed statements can be difficult to interpret since the participants are instructed to sort the statements from those they most agree with to those that they most disagree with. Statement no. 44: 'user participation is non-existent, no one ask the patients, is both a negatively expressed statement that can also be described as an extreme statement. One should also attempt to avoid extreme statements. Watts and Stenner's (2012) recommendation is to adjust statements towards more neutral meanings. For example, statement 44 could be reformulated like this: "I am satisfied with the degree of user participation." The essence or meaning in the statements would be the same, but more nuances among the participants could be revealed by their placement in the grid (Figure 2). One should also try to avoid double-barrelled statements (Watts & Stenner, 2012) such as statement no. 22: I'm not against coercion, but I am against unnecessary coercion. For some participants, it could be difficult to decide whether they should put an emphasis on the first part of the statement: I am not against coercion, or on the last part, which is about unnecessary coercion. However, it is interesting that when it comes to statement 22, both one patient and one staff member commented during the sorting process that in this statement the essence of challenges related to coercion was summarized. Since one of the researchers was present with the participants, both when they sorted the statements and when they participated in the post-interview, it was possible to avoid some of these misunderstandings. If the participants found during their reflections that they had misinterpreted one or more of the statements on the most

agree or most disagree side of the grid (Figure 2), it was revealed to some degree during the post-interview. Misunderstandings could then be avoided, and adjustments in the grid (Figure 2) could be done if the participants wanted to do so.

Even if the use of post-interviews as a part of the analysis process is recommended, it needs some consideration. As described in papers I- III, the participants were interviewed after they had sorted the statements, although there is one aspect of doing post-interviews not discussed by Gallagher and Porock (2010) that needs to be considered. In study 1 among staff members (paper I), and in study 3 (paper III) among relatives, some participants were found to be confounded, or not loading significantly on one of the factors, and were therefore excluded from further analysis . Maybe this is not a methodological problem, but it can be a problem for ethical research. As described by Gallagher and Porock (2010), it is time consuming for the participants participate in the post-interviews. The participants also have expectations that their stories are important for the researchers. The fact that researchers do not use information they have received during the post-interviews because the participants are excluded from further analysis as a result of statistical analysis is a problem for ethical research. Gallagher and Porock (2010) describe the separation of Q sorting and post-interviews as an opportunity, which means that some of the disadvantages with participants who are excluded from further analysis could then be avoided. Hence, post-interviews could then be done at a later time with only those participants who loaded significantly on only one factor.

But at the same time, the use of post-interviews is a strength of these studies. As several authors have argued (Ellingsen, 2010; Brown, 1980; Gallagher, 2010), a strength of doing Q methodological research is that it is each participant's unique interpretation and sorting of statements that results in creating like-mindedness groups, thereby establishing viewpoints for further interpretation by the researcher. Post-interviews from the participants were of major importance when interpreting what was communicated through the viewpoints, with one example of this possibly being the study among staff members (paper I), viewpoint 2, "Challenges for staff". Comments such as, "I feel that I have to sit down and think about why I react as I do", was interpreted as the focus being on challenges that the staff experienced in their encounters with patients.

As discussed in papers II and III, when doing Q methodological research it is not a question of generalizing from the participants to a wider population, but that establishing the existence of the viewpoints could have consequences for a wider population. Watts and Stenner (2012) emphasize the importance that establishing the existence of viewpoints can be a powerful way to undermine established preconceptions. Another way of saying this is that the viewpoints explored in studies 1–3 challenge our way thinking about how to take care of patients' dignity.

7.2 METHODOICAL CONSIDERATIONS RELATIVE TO PHENOMENOLOGICAL HERMENEUTICS METHOD FOR RESEARCHING LIVED EXPERIENCE

In paper IV, Lindseth and Norberg's (2004) phenomenological hermeneutic method for researching lived experience was used as an approach for an analysis of the interviews, and there were two reasons for choosing this methodological approach. Most importantly was the wish to analyse the qualitative interviews with patients and relatives for a purpose other than selecting a wide range of statements from the concourse for developing a Q sample for studies 1–3 (paper I-III). By using the phenomenological hermeneutic method for researching lived experience as a methodological approach, we were searching for whether there were additional aspects to reveal what was found by using a Q methodological approach alone. The reason for choosing the phenomenological hermeneutic method for researching lived experience as developed by Lindseth and Norberg (2004) was their description of Edmund Husserl's "Emphasis on essential meaning". Lindseth and Norberg (2004) also describe how one needs to assume that there exist such essential meanings. Essential meaning is important for communication between people, even if we as human beings do not need to be conscious of these meanings. By using the phenomenological hermeneutic method for researching lived experience new meanings, in this case, "The significance of small things for experience of dignity", was revealed through the analysis.

8 CONCLUSION

The presented findings underscore the importance of maintaining a focus on dignity in mental health care. Within each group of patients, relatives and caregivers, both consensus and differences among the participants were found. By looking at all studies at the same time, some similar experiences were also found across the studies.

Within all the groups of patients, relatives and staff members, some of them emphasized the importance of keeping a focus on values such as equality and respect for humans uniqueness with regard for taking care of the patient's dignity. For staff members, by taking a compassionate care approach and being aware of a patient's vulnerability, one's ethos became visible through ethical caring.

This study has shown that patients still experience being in a position of imbalance in their relationship towards carers. Despite a focus on user participation as a legal right in mental health-care, patients still experience suffering and reduced dignity as a result of this imbalance. For caregivers, it is important that they do not forget that their way of being towards patients results in increased patient suffering, which is something that decreases their experience of dignity. Some patients (and relatives) also seem to find meaning in their experiences, something which alleviates their suffering. For caregivers, being aware of- and recognizing a patient's suffering opens up an opportunity for a compassionate self in an authentic encounter with patients. For patients, this can result in being met in a compassionate way.

An awareness of small things was emphasized in this study and discussed in paper IV. Maybe it is simple, but at the same time complicated, as to how staff members behave towards patients (and also relatives) in each unique encounter with them as human beings, whether in a dignity promoting or dignity inhibitory way, reveals to what degree staff are aware of their ethos, as well as to what degree both the individual staff members and the caring culture can be described as ethical or not ethical.

9 SAMANDRAG PÅ NORSK

Bakgrunn: Betydinga av å respektere menneskets ibuande verdigheit vart for alvor satt på agendaen gjennom FNs verdserklæring om menneskerettigheter. Også frå eit omsorgs vitskapleg perspektiv er det framheva betydinga av å møte mennesket med respekt og ivareta deira ibuande verdigheit. Til tross for detta opplever pasientar ved psykiatriske sjukehus framleis liding og redusert verdigheit.

Hensikt: Overordna hensikt med denne studia var å utforske og få innsikt i erfaringane til pasientar, pårørandes og personale ved psykiatriske sjukehus i forhold til ivaretaking av pasientens verdigheit. I artikkel I var målet å få djupare forståing for korleis personale oppfattar verdigheit i møtet med pasientane, og kva dei meiner påverkar pasientanes oppleving av verdigheit. I artikkel II var målet å få ei djupare forståing for pasientar ved psykiatriske sjukehus si oppleving av verdigheit. Hensikt med studie III var å avdekke kva pårørande meiner at er viktig for å ta vare på pasientens verdigheit når de var innlagt på psykiatrisk sjukehus. I studie IV var fokuset på felles erfaringane hjå pasientar og pårørande til pasientar i forhold til å ivareta pasientanes verdigheit når de er innlagt på psykiatrisk sjukehus.

Metode: To forskjellige metodologiske tilnærmingar vart nytta. I studie 1, 2 og 3 er Q metodologisk tilnærming anvendt. Basert på eit Q-utval (samling av utsegn) utvikla på grunnlag av kvalitative intervju vart pasientar, pårørande og personale instruert til å sortera 51 utsegn. Pasientane vart instruert om å sortere utsegna, i ei matrise, ut i frå kva dei var mest samde i til kva dei var mest usamde i. Pårørande og personale sorterte utsegna ut i frå kva dei meinte var relevant for pasientens oppleving av verdigheit. Etterintervju vart gjennomført med deltakarane like etter at dei hadde sortert utsegna. I både personale studia (artikkel I), pasient studia (artikkel II) og pårørande studia (artikkel III) vart analyse av data gjort ved hjelp av faktoranalyse. I studie 4 vart fenomenologis hermeneutisk metode for forskning på levd erfaring nytta for å analysere dei kvalitative intervju med pasientar og pårørande.

Resultat: I studie 1 (artikkel I) deltok 25 personale og to ulike synspunkt kom til syne. Synspunkt 1 har fått namnet 'Pasient fokuserte personale'. Synspunkt 2 vart skildra som 'Utfordringar for personale'. I studie 2 (artikkel II) deltok 15 pasientar og fire ulike synspunkt kom til syne. Synspunkt 1 vart kalla 'Å bli møtt som likeverdig menneske'. synspunkt 2 fekk namnet 'Oppleving av verdigheit til tross for liding'. Synspunkt 3 er blitt tolka som 'Liding på grunn av følelse av mindreverd'. Synspunkt 4 vart skildra som 'Liding og kamp for eiga verdigheit'. Studie 3 (artikkel III) handla om pårørande sine synspunkt. 13 pårørande deltok og fire ulike synspunkt vart identifiserte. Synspunkt 1 fekk namnet 'Verdibasert'. Synspunkt 2 omhandla 'Forventningar'. Synspunkt 3 handla om 'Asymmetri' i forholdet mellom partane. Synspunkt 4 vart skildra som 'Nyansert'. I studie 4 (artikkel IV) vart det avdekka eit hovudtema og fire undertema. Hovudtemaet vart skildras som 'Dei små tings betyding for oppleving av verdigheit'. Dei fire undertema fekk namna: 'Å være bevisst de små ting', 'Å være bevisst på kva ein seier', 'Å bli møtt' og 'Å være oppmerksom på personlig kjemi'.

Konklusjon: Innafor kvar gruppe av pasientar, pårørande og omsorgspersonale vart det funnen likskap men også ulikskap hjå deltakarane. Også likskapar mellom dei ulike studiane vart det funne. Personale si måte å møte pasientar og pårørande på hadde direkte innverknad på pasientane sin oppleving av verdigheit. I møter der pasientar og pårørande opplevde å bli møtt av personale som representerar verdiar som likskap og respekt for det unike i mennesket så opplevde dei at pasientens verdigheit vart ivaretatt. Personale la også vekt på dette, og nokre personale hadde hovudfokuset på dette. Andre personale fokuserte også på eigne utfordringane i møtet med pasientane. Nokre pasientar og pårørande formidla at det framleis var ubalanse forhold til personale, noko som førte til auka liding for pasientane. Andre pasientar og pårørande vurderte det som nokon gongar naudsynt at personale overtok ansvar for pasientens situasjon. Når omsorgspersonale er klar over deira ansvar overfor pasientens liding og lider med pasientane så opnar det opp for eit mellommenneskelige møte som kan bidra til lindring av pasientanes liding og ivaretaking av deira verdigheit. Som diskutert i artikkel IV så er måten personale er overfor pasientane, i kva grad dei har fokus på små ting i kvart unike møte med pasientane, om det opplevast verdigheitsfremjande eller verdigheitshemmande, så avdekkar det i kva grad personale er klar over eige etos, og i kva møtet med det enkelte personale, men også omsorgskulturen kan opplevast som etisk eller uetisk av pasientane.

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